

# **Can people with learning disabilities report their own psychotic symptoms?**

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# Abstract

People with learning disabilities (PWLD) have an increased risk of developing poor mental health due to social, psychological, economic, emotional and biomedical factors. The identification and correct diagnosis of mental health problems in learning disabled adults is complex and can be highly challenging even for the most experienced clinicians. This complexity is confounded by the lack of validated assessment tools to support an accurate diagnosis. The overall purpose of this research was to develop, implement and evaluate an Easy Read set of psychotic statement sort-cards to assist PWLD, who have suffered from psychosis, in the identification of their individual psychotic symptoms.

This research was undertaken in two parts. Study 1 comprised of a series of focus groups with people with learning disabilities. A total of thirty-eight participants participated in five focus groups. The focus groups involved asking the participants to comment on the wording of fifty-four psychotic symptom statements and then to choose from two Widgit symbols that they thought best supported the statement. The aim of the focus groups was to establish the appropriateness of Easy Read information on psychotic symptoms which could be used to develop a sort-card tool. The sort-card tool was utilised within Study 2.

In Study 2, a different sample of people with learning disabilities and a diagnosis of psychosis were interviewed using semi-structured interviews that incorporated the Easy Read sort-card tool, to establish if the participants could report their own psychotic symptoms and lived experiences. Study 2 used a qualitative research method, in the form of Interpretative Phenomenological Analysis (IPA) to build an understanding of the participant's narratives. Nine participants, who were patients of the local Specialist Health Learning Disability Service, elected to participate in the study. This part of the study also employed clinical descriptions of each of the participant's diagnostic characteristics to relate to the participants reporting. The results of the study revealed that, by

introducing an Easy Read psychotic symptom sort-card tool, the participants were able to label and frame their individual experiences and, in doing so, they were empowered to narrate a detailed description of their psychotic symptomology. Armed with a detailed description of their individual symptoms, the participants went on to identify their own timeline of symptoms that manifested within the prodromal and active stages of their psychosis.

The most poignant finding was the significant levels of trauma that had been experienced by the participants and the direct impact this had on their mental health resilience. The findings have considerable implications for clinical practice, especially on the education of Learning Disability Nursing, in adopting a formulation approach that lends itself to understanding the individual's unique experiences, rather than the current service delivery which has traditionally been tied to strict diagnostic criteria.

<b>Table of Contents</b>	<b>Page</b>
Abstract	i
Table of contents	iii
List of Appendix	ix
List of tables	x
List of figures	xi
Acknowledgements	xiii
Declaration	xiv
Anonymity statement	xv
List of abbreviations	xvi

## **Chapter 1: Introduction**

1.1. Introduction	1
1.2. The rationale of the research	2
1.3. Reflexivity of the author	3
1.4. Aims of the Thesis	4
1.5. Overview of the Thesis	5

## **Chapter 2: Literature review**

2.1. Introduction	8
2.2. The literature review	10
2.3. The definition and terminology of learning disability	11
2.4. The prevalence of learning disability	13
2.5. History of learning disability	15
2.6. Mental illness	22

2.7.	Early intervention	25
2.8.	Learning disability and mental illness	29
2.9	Current clinical practice for PWLD with mental health difficulties	35
2.10.	Augmentative and Alternative Communication (ACC)	37
2.11.	Augmentative and Alternative Communication (ACC) and learning disability	42
2.12.	Research in learning disabilities	46
2.13	Summary	50

### **Chapter 3: Methodology**

3.1.	Introduction	53
3.2.	Research paradigms	54
3.3.	Methodology	57
3.3.1.	Phenomenology	59
3.3.2.	Hermeneutics	62
3.3.3.	Idiography	63
3.4.	Interpretative Phenomenological Analysis (IPA)	64
3.4.1.	Rationale for selecting IPA	65
3.4.2.	Limitations of IPA	68
3.5.	Considerations of alternative approaches	69
3.6.	The epistemological position of the author	71
3.7.	Research design	74
3.8.	Preliminary planning	76
3.8.1.	Adapting psychotic statements into Easy Read	76

3.8.2.	Symbol selection	81
3.9.	Details of study 1: Development of a sort-card tool	83
3.10.	Study 2: Implementing a sort-card tool	84
3.11.	Participants	85
3.12.	Data collection	87
3.13.	Ethical considerations	87
3.13.1.	Ethical approval for the studies	89
3.13.2.	Informed consent	89
3.13.3.	Privacy and Confidentiality	90
3.13.4.	Participants wellbeing	91
3.14.	Data analysis	91
3.15.	Conclusion	93

## **Chapter 4: Study 1- Development of a sort-card tool**

4.1	Introduction	94
4.2.	Method	94
4.2.1.	Recruitment of participants	94
4.2.2.	Participants	96
4.2.3.	Focus group procedures	96
4.3.	Data analysis and findings	99
4.4.	Conclusion	113

## **Chapter 5: Study 2- Implementing an Easy Read sort-card tool**

5.1.	Introduction	115
5.2.	Method	115
5.2.1.	Recruitment of the participants	117

5.2.2.	Participants	119
5.2.3.	Structure of the interview schedule	123
5.3.	Data collection	129
5.4.	Data analysis	130
5.5.	Findings	132
5.6.	Conclusion	138

## **Chapter 6: Findings**

6.1.	Introduction	139
6.2.	Part one of the interviews: symptom reporting	141
6.3.	Super-ordinate themes and corresponding sub-ordinate themes from part two of the interview	146
6.3.1.	Super-ordinate theme A: Understanding the sort-cards	146
6.3.1.1.	Theme A1: Widgit symbols	147
6.3.1.2.	Theme A2: Asking for further clarification	148
6.3.1.3.	Theme A3: Literal understanding	148
6.3.1.4.	Theme A4: Other relevant data	149
6.3.2.	Super-ordinate theme B: Additional symptoms	149
6.3.2.1.	Theme B1: Eating	150
6.3.2.2.	Theme B2: Sleep	150
6.3.2.3.	Theme B3: Physical changes	150
6.3.2.4.	Theme B4: Changes in activities	150
6.3.2.5.	Theme B5: Talking and smiling to myself	150
6.3.2.6.	Theme B6: Withdrawal	151
6.3.2.7.	Theme B7: Other additional experiences	152
6.3.3.	Super-ordinate theme C: Underlying causes	152

6.3.3.1.	Theme C1: Trauma	152
6.3.3.2.	Theme C2: Hope and despair	153
6.3.4.	Superordinate theme D: Additional symptom description	154
6.3.4.1.	Theme D1: Feelings and emotions	154
6.3.4.2.	Theme D2: Visual hallucinations	155
6.3.4.3.	Theme D3: Auditory hallucinations	155
6.3.4.4.	Theme D4: I feel more religious	156
6.3.4.5.	Theme D5: I have strange feelings in my body	156
6.3.4.6.	Theme D6: I think a part of me has changed shape	156
6.3.4.7.	Theme D&: Difficulty sleeping	156
6.3.4.8.	Theme D8: I think I might be someone else	157
6.3.4.9.	Theme D9: There is something I can't stop thinking about	157
6.3.4.10.	Theme D10: I feel far away, in a different world	157
6.3.4.11:	Theme 11: I act like people are watching me	157
6.3.4.12:	Theme D12: Individual symptom descriptions	157
6.3.5.	Super-ordinate theme E: Time-line	158
6.3.5.1.	Theme E1: Symptoms all the time	159
6.3.5.2.	Theme E2: Grouping symptoms	159
6.3.5.3.	Theme E3: Thoughts, feelings and behaviours	160
6.3.5.4.	Individual timelines	163
6.4.	Conclusion	166



## **Chapter 7: Discussion**

7.1.	Introduction	168
7.2.	Preliminary planning	169
7.3.	Findings and discussion of Study 1	170
7.4.	Discussion of Study 2	170
7.4.1.	Part one of the interview: symptom reporting	171
7.4.2.	Super-ordinate theme: Understanding the sort-cards	175
7.4.3.	Super-ordinate theme: Additional symptoms	176
7.4.4.	Super-ordinate theme: Underling causes	178
7.4.5.	Super-ordinate theme: Additional symptom description	181
7.4.6.	Super-ordinate theme: Timeline	183
7.5.	Care Plans	185
7.6.	Additional areas for discussion	187
7.7.	Implications for clinical practice	189
7.8.	Conclusion	190

## **Chapter 8: Conclusion and Recommendations**

8.1.	Introduction	192
8.2.	Focus of this research	192
8.3.	Strengths and limitations	193
8.4.	Implications for future research	196
8.5.	Evaluation of the research and recommendations	197
8.6.	Reflection on undertaking the research	199

8.7	Dissemination	202
8.8	Conclusion	203

<b>References</b>	204
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## **List of appendices**

Appendix 1	My thought statements with two Widgit symbols	251
Appendix 2	My feeling statements with two Widgit symbols	256
Appendix 3	My behaviour statements with two Widgit symbols	260
Appendix 4	Ethical approval letter from De Montfort University	266
Appendix 5	Ethical Approval letter from HRA	267
Appendix 6	Focus group poster	268
Appendix 7	Information sheet for participants for Study 1	269
Appendix 8	Information sheet for carers for Study 1	273
Appendix 9	Consent form for Study 1	275
Appendix 10	Hampshire Partnership mental illness booklet	278
Appendix 11	Behaviour sort-cards	281
Appendix 12	Feelings sort-cards	284
Appendix 13	Thoughts sort-cards	287
Appendix 14	Clinician information sheet for Study 2	290
Appendix 15	Clinician consent form for Study 2	293
Appendix 16	Information sheet for participants for Study 2	294
Appendix 17	Information sheet for carers for Study 2	299
Appendix 18	Referral form for Study 2	302
Appendix 19	Invitation to attend interview for Study 2	303

Appendix 20	Data collection form for Study 2	308
Appendix 21	Consent form for Study 2	310
Appendix 22a	Participant 1 (Paul) Care plan	313
Appendix 22b	Participant 1 (Paul) interview transcript	316
Appendix 23a	Participant 2 (Sally) Care plan	329
Appendix 23b	Participant 2 (Sally) interview transcript	335
Appendix 24a	Participant 3 (Robert) Care plan	359
Appendix 24b	Participant 3 (Robert) interview transcript	364
Appendix 25a	Participant 4 (Linda) Care plan	388
Appendix 25b	Participant 4 (Linda) interview transcript	391
Appendix 26a	Participant 5 (Jim) Care plan	401
Appendix 26b	Participant 5 (Jim) interview transcript	403
Appendix 27a	Participant 6 (Keith) Care plan	427
Appendix 27b	Participant 6 (Keith) interview transcript	430
Appendix 28a	Participant 7 (Paula) Care plan	450
Appendix 28b	Participant 7 (Paula) interview transcript	452
Appendix 29a	Participant 8 (Tilly) Care plan	464
Appendix 29b	Participant 8 (Tilly) interview transcript	466
Appendix 30a	Participant 9 (Sam) Care plan	487
Appendix 30b	Participant 9 (Sam) interview transcript	489

## **List of tables**

Table 1	Amended psychotic symptom statements	77
Table 2	Flesch Reading Score levels	80
Table 3	Flesch readability scores after amendments	81
Table 4	Results of the focus groups chosen Widgit symbols for thoughts	100

Table 5	Results of the focus groups chosen Widgit symbols for behaviours	102
Table 6	Results of the focus groups chosen Widgit symbols for feelings	104
Table 7	Demographics of participants	122
Table 8	Results of sort-card selection for each participant	135
Table 9	Super-ordinate and sub-ordinate themes	140

## **List of figures**

Figure 1	Psychotic prodromal illustration	28
Figure 2	Rebus symbols	38
Figure 3	Bliss symbols	39
Figure 4	Makaton symbols	39
Figure 5	Picture Communication symbols	39
Figure 6	Widgit symbols	46
Figure 7	Study design	75
Figure 8	Example of best for Widgit symbol for each symptom statement	83
Figure 9	Focus group with psychotic symptom statement together with two Widgit symbols	98
Figure 10	Example of cards within sort-card tool	108
Figure 11	Focus group suggested amendments to Widgit symbols	110
Figure 12	Focus group suggested amendments to Widgit symbols	111
Figure 13	Focus group suggested amendments to Widgit symbols	112
Figure 14	Focus group suggested amendments to Widgit symbols	113

Figure 15	Prompt card	125
Figure 16	Example of sort-card exercise	128
Figure 17	Example of sort-card exercise	128
Figure 18	Total amount of symbols chosen by each participant	133
Figure 19	Number of chosen behavioural symptoms	164
Figure 20	Number of chosen thought symptoms	165
Figure 21	Number of chosen feeling symptoms	166
Figure 22	Care plan over-arching statement	186
Figure 23	Sort-card that the participants found difficult to understand	187
Figure 24	Example of additional descriptions added to individual participants symptom statements	188

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## Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctorate in Health Science Programme (DHSci) is entirely my own work and that I have exercised reasonable care to ensure that the work is original and does not, to the best to my knowledge, breach any law of copyright.

A handwritten signature in black ink that reads "Ward". The signature is written in a cursive style with a large, looped 'W' and a trailing 'd'.

Signed:

Gaynor Ward (Candidate)

ID Number: P10549839

Date: April 2019

## **Anonymity statement**

All the participants have been anonymised with a pseudonym.

The names of the areas they have lived in, services that support them and members of the staff have not been used.

All other personal identifiers, such as dates of care plans, and the names of relatives have been anonymised.



## List of abbreviations

AAC	Augmentative and Alternative Communication
DC-LD	Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disability/Mental Retardation
DSM	Diagnostic and Statistical Manual for Mental Disorders
ICD-10	International Classification of Disease issue 10
IPA	Interpretative Phenomenological Analysis
IQ	Intelligence quotient
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NK	Not known
PAS-ADD	Psychiatric Assessment Schedule for Adults with Developmental Disabilities
BPD	Borderline Personality Disorder
PWLD	People with learning disability
REC	Research Ethical Committee
R & D	Research and development
UK	United Kingdom

# Chapter 1: Introduction

## 1.1. Introduction

Until as recently as the 1980s, it was still believed that people with learning disabilities (PWLD) did not have the cognitive capacity to experience mental illness. This belief that PWLD are not susceptible to mental illness is no longer valid (Raghavan and Patel, 2005) as it is now known that they do experience the same mental ill-health as adults without such disability and that they are, in fact, probably more vulnerable.

PWLD have an increased risk of developing poor mental health due to social, psychological, economic, emotional and biomedical factors. However, there are many barriers to early identification and diagnosis of psychosis for PWLD. The Count Us in Inquiry (Foundation for People with Learning Disabilities, 2002) identified diagnostic overshadowing, carers and professionals lack of knowledge, feeling that people with learning disabilities are not listened to, referrals passed from service to service and communication difficulties as key barriers.

This barrier of early identification and diagnosis of psychosis for this population is further compounded by the dearth of suitable assessment tools. Most tools that assess for psychiatric disorders are not validated for the learning-disabled population. The tools that have been validated rely on carer or clinician reporting only; the person themselves is never consulted about their symptoms. This reliance on third party reporting may stem from a perceived difficulty in ascertaining self-reported symptoms as there is a common discernment that PWLD have communication difficulties, suggestibility, poor recall, and are prone to acquiescence bias, resulting in the individual themselves being denied personal expression. Furthermore, this strong emphasis to gain subjective reports from other people, such as family members and care staff, and to use assessment tools that screen from the viewpoint of the caregiver does not allow

for a comprehensive assessment to be undertaken and could lead to under or misdiagnosis (Moss, 2012). The overall purpose of this thesis was to develop, implement and evaluate an Easy Read symptom sort-card tool to assist PWLD, who have suffered from psychosis, in the identification of their individual psychotic symptoms. A qualitative research methodology in the form of Interpretative Phenomenological Analysis (IPA) was used.

## **1.2. The rationale of the research**

One key issue is the high prevalence rates of psychosis in this population group. Research shows that the prevalence rate of a diagnosable psychiatric disorder is reported to be at a higher percent compared with those who do not have a learning disability (Emerson *et al.*, 2014, 2015, 2016; Hatton, *et al.*, 2015; Robertson *et al.*, 2014), with prevalence rates for schizophrenia in PWLD being three times greater than for the general population (Emerson, 2011).

In the Health and Social Care Information Centre census (NHS Digital, 2015) it was reported that over 3,000 PWLD are in receipt of psychiatric in-patient services, with 305 individuals in the East Midlands region alone. Of these, 72 percent were detained under the Mental Health Act 1983 and 70 percent were in receipt of antipsychotic medication. Furthermore, it is estimated that on an average day in England between 30,000 and 35,000 PWLD are taking prescribed psychotropic medication without appropriate clinical justification. Long-term use of these medicines puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death (NHS England, 2016).

In the general population, mental health problems are usually assessed primarily at a clinical interview where the psychiatrist asks the patient first about current symptoms and difficulties. They then ascertain information on an ever-widening circle of other experiences and events, past and present, but this

exercise often proves too sophisticated for PWLD because of their poor verbal ability and lack of insight.

### **1.3 Reflexivity of the author**

Reflexivity is of paramount importance in qualitative research, as it helps us understand the characteristics and experiences of the researcher and how this may impact on the research in question. It allows the researcher to consider the influences that have shaped their attitudes, assumptions and positionality.

I am a white, heterosexual woman, from the East Midlands, who was born into a working-class family. Growing up, my father was a policeman and my mother was a stay-at-home parent. Although there was an emphasis on academic achievements for my brother, as a female the same expectations were not afforded to me. The bias was towards a more stereotype female role for that era, being a secretary or housewife. Therefore, my expectations of a carer were low, if not non-existent, and found myself embarking on an employment path of barmaid and catering assistant.

So, I was equally surprised as the rest of my family, when I stumbled on nursing. I started my studies at the time when the new 1982 curriculum had just been introduced. The emphasis of the syllabus revolved around the demise of institutional care and the growth of a new social model of disability, propelled by the theories of social role valorisation, normalisation, Wolf Wolfensberger and John O'Brien. Although the philosophy and terminology were changing; I was no longer studying to be a mental subnormality nurse but a mental handicapped nurse, the reality of being a hands-on staff member on large wards, within the institution remained the core of my training.

It was not until a few years after qualifying, having moved to community care, that I started to embark on post qualification studies and my practice and research orientation became more united. In studying epilepsy, I took a more

positivist position, believing the role of the researcher, and practitioner, was that of an objective observer of fact, rather than an active participant in the co-creation of knowledge and co-facilitator of theoretic change. Influenced by scientific publications I pursued by practice with neatly labelled, sorted categories that could be clearly defined, measured and solved. Although, looking back I realise I was uncomfortable with the lack of person-centred models of practice, I found strength and prestige from the comfort of randomised control trials and the status quo.

Over the later decade of my career, I have specialised in mental illness. In clinical practice, the complexities of assessing mental health difficulties in PWLD became more and more evident, especially as the processes to assess mental illness in the general population are not transferable to PWLD and there is an absence of formalised tools to ascertain PWLD's lived experience. I began to embrace the concepts of multiple truths and acknowledged that truth is dependent on time, context and previous experience. The paradigm of social constructivism enlightened me to the concept that knowledge can be subjective, with truth lying within human experience, that is culturally and context bound. The recognition that truth and meaning do not exist in some external world but are created by the individual's interactions with the world became the motivation for this study. Surely, psychotic symptoms should be examined from the person's experiences rather than a decontextualised approach of symptoms of a disorder and pathological biological process. The question was, if such a tool were available to enable a PWLD to report their lived experiences, and they were empowered to do so, could they use it to report their own psychotic symptoms and development of their own relapse signature?

#### **1.4. Aims**

The literature review enabled the researcher to confirm that there is an absence of evidence of individuals with learning disability being supported to self-report their psychotic symptoms or lived experience. Given the lack of research into

how PWLD experience and self-report their psychotic symptoms, this research aimed to elucidate and evidence that when PWLD are given the right Easy Read resources they can identify their own symptoms.

The underlying objectives of this research were to develop, implement and evaluate an Easy Read set of sort-cards to assist PWLD, who had been diagnosed with psychosis, in the identification of their individual psychotic symptoms. A qualitative research methodology was used in the form of focus groups and semi-structured interviews.

The objectives of the research were conducted in two interlinked phases being:

**Study 1:** Developing an Easy Read psychotic symptom sort-card tool.

1. To explore and identify with PWLD an appropriate symbol that matches a description of a symptom of psychosis.
2. To use the chosen symbol together with the symptom description to create a set of Easy Read sort-cards.

**Study 2:** Implementing and evaluating the Easy Read psychotic symptom sort-cards tool.

3. To explore if the Easy Read sort-cards can enhance the reporting of psychotic symptoms for PWLD.

## **1.5. Overview of the Thesis**

**Chapter 2: The literature review.** This chapter provides an exploration of the literature process and the results of the literature search on issues related to adults with learning disabilities and psychosis. It includes a definition and prevalence of learning disability, together with a historical perspective. The chapter goes on to review the literature on mental illness and early

interventions. Within this chapter augmentative and alternative communication are also discussed.

**Chapter 3: Methodology.** This chapter explores the research methodology, beginning with the philosophical framework. Influential disciplines and schools of epistemological thought are referred to and how these relate to the author's position. The strategic and methodological frameworks are also included. Specific details of the research design including; preliminary planning required for the next part of the research, explanation of how Study 1 and Study 2 interlink, participants, ethical considerations, data collection and analysis are presented.

**Chapter 4: Study 1: Development of a sort-card tool.** Chapter four presents the method and the results of Study 1, involving running focus groups, to create an Easy Read sort-card tool. The focus groups were able to identify fifty-four psychotic statements together with a matching Widgit symbol.

**Chapter 5: Study 2: Implementing an Easy Read sort-card tool.** This chapter describes the implementation of the sort-card tool which was developed within Study 1. This includes an explanation of the interview schedule. Details of the data collection, data analysis and findings are also offered.

**Chapter 6: Findings.** Within chapter six the results from Study 2 are discussed. This was undertaken by using an IPA framework. Five super-ordinate themes emerged that linked directly to the participant's narratives.

**Chapter 7: Discussion.** The first part of this chapter initially focuses on the preliminary development stage and Study 1. The chapter continues with a more detailed discussion of the findings from Study 2. It also includes implications for clinical practice.

**Chapter 8: Conclusion.** This chapter concludes the research results. Limitations, next steps and recommendations for further research are also considered in this chapter.



## Chapter 2: Literature review

### 2.1. Introduction

On the same day that the Government published its response to the Five Year Forward View for Mental Health (NHS England, 2016), the Prime Minister announced a comprehensive package of measures to transform mental health support in schools, workplaces, and communities (Mind, 2017). Most of us experience challenges around our emotional well-being at some stage in our lives, with one in four of us experiencing a problem with our mental health in any one year. Children and adults with learning disabilities and other forms of disabilities are not exempt from this. For people with learning disabilities (PWLD), the prevalence rate of a diagnosable psychiatric disorder and more problematic health behaviours is reported to be at a higher percent compared with those who do not have a learning disability (Emerson *et al.*, 2014, 2015, 2016; Hatton *et al.*, 2015; Robertson *et al.*, 2014) with prevalence rates for schizophrenia in PWLD being three times greater than for the general population (Emerson, 2011).

As the large asylums closed, the National Health Service (NHS) acute psychiatric provision did not have the capacity to support PWLD and consequently the demand rose for low and medium secure facilities to be provided by the private sector. This trend continued until investigations began in the aftermath of the Winterbourne View revelations (Department of Health, 2012). From this inquiry, it was apparent that NHS hospital episode statistics did not provide a comprehensive view of psychiatric in-patient care for PWLD, as private hospital provision was not required to submit data that is mandatory for the NHS. Findings from a series of censuses of all psychiatric in-patient facilities, initiated by the Mental Health Act Commission in 2006 and continued until 2010, by its successor the Care Quality Commission, suggested that in 2010, out of a total of 3,642 current psychiatric in-patients with learning

disability, 32.5 percent were in private hospitals with 45 percent staying on wards described as 'long-stay' or 'rehabilitation'.

NHS Digital (2015), reported that a total of 3,230 PWLD received psychiatric in-patient services, with 305 individuals in the East Midlands region alone. Of these, 72 percent were detained under the Mental Health Act 1983 and 70 percent were in receipt of antipsychotic medication. Furthermore, it is estimated that on an average day in England between 30,000 and 35,000 PWLD are taking prescribed psychotropic medication without appropriate clinical justification. Long-term use of these medicines puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death (NHS England, 2016).

A later report published by Public Health England (2016) identified that of the cohort of PWLD who were in psychiatric beds in both 2013 and 2014, 45 percent were still in hospital a year later and for those in medium secure beds the figures of lengthy detention rose to around 80 percent.

These figures reflect experiences within the clinical field, yet there is no consensus on assessment of mental illness in PWLD. In the general population, mental health problems are usually assessed primarily at a clinical interview where the psychiatrist asks the patient first about current symptoms and difficulties. They then ascertain information on an ever-widening circle of other experiences and events, past and present, but this exercise is predominately difficult to undertake with PWLD because of their poor verbal ability and lack of insight. Therefore, a strong emphasis is placed on reports from other people such as family members and care staff and use of assessment tools that screen from the viewpoint of the caregiver (Moss, 2012).

As people with a mild learning disability can communicate verbally and relate their experiences they should be able to access generic mental health services. Although United Kingdom Government policy and guidance strongly advocates the use of mainstream healthcare by PWLD (Department of Health, 1999, 2001; Cole, 2002; Foundation for People with Learning Disabilities, 2002, 2004;

National Development Team, 2013) there is still lack of equitable access. This is exacerbated by many professional staff attributing symptoms of mental health problems to the person's learning disability; often referred to as diagnostic overshadowing (Joint Commissioning Panel for Mental Health, 2013; Parish, 2017), or learning disability professionals thinking they do not have the expertise to deal with mental health problems, while mental health services do not think they have the expertise to support PWLD (Dean, 2014).

The motivation for this research stemmed from working within the field of learning disability nursing for over thirty years. For the latter decade of the researcher's (first author) professional career they have supported services to create a vision on how to work in partnership with PWLD and have aided NHS mental health providers to deliver a better understanding of the mental health needs of adults with learning disabilities. By undertaking this clinical work, the complexity of assessing mental health difficulties in this population is evident. There is also recognition that there are no formalised tools to ascertain a PWLD's lived experience of their psychotic illness.

If such a tool was available, and PWLD were empowered to do so, could they report their own psychotic symptoms, specifically within the prodromal stage of the illness to aid diagnosis, treatment, appropriate support, and to help in the development their own relapse signature?

## **2.2. Literature review**

A literature search was conducted in December 2015 and continued to present day, using databases CINAHL and United States National Library of Medicine's bibliographic database (MEDLINE), American Psychological Association (PsycINFO), Excerpta Medica Database (EMBASE), Health Management Information Consortium (HMIC) and Cumulative Index to Nursing and Allied Health Literature (CINHAL). The search terms 'Learning Disability', 'Intellectual Disability', 'Mental Retardation', 'Mental Handicap', 'Developmental Disabilities' paired with 'Psychosis', 'Mental Health', 'Schizophrenia', 'Bipolar mood

disorder', 'Manic depression', 'Easy Read', 'augmentative and alternative communication', 'assessment', 'symptoms', 'self-reporting' were used. Other clinicians engaged in similar work and tracking of citations from reference lists on guidance documents was also undertaken.

### **2.3. The definition and terminology of learning disability**

'Learning disability' means many things to different people (Gates, 2007) and no single criterion provides a conclusive answer to its essence. It is a complex and multi-faceted concept, but it is widely agreed that the condition is from birth, or developed during infancy or childhood, and must be present before the age of eighteen years.

Intelligence quotient (IQ) is normally distributed in the population, with the average IQ being 100, with a range of 15 points either side. Therefore, anyone with an IQ score between 85 and 115 is said to be of average intelligence. The International Classification of Disease (ICD-10): Classification of Mental and Behavioural Disorders (World Health Organisation, 1992) definition of learning disability requires the person to have an IQ of less than 70. Further sub-classifications are categorised as; mild- with an IQ range of 50 to 70 (or 9 to under 12 years of age); moderate- with an IQ range of between 35-49 (or under 9 years of age); severe being in the IQ range of 20-34 (or under 6 years of age); and profound falling under the IQ range of 20 (or below 3 years of age). Learning disability is further defined as a state of arrested or incomplete development of the mind (WHO, 1992).

Previously, a diagnosis of a learning disability and the understanding of a PWLD's needs was solely based on IQ scores. More recently there has been considerable scientific debate questioning the accuracy of IQ testing for PWLD, with claims that the IQ score is of little relevance and IQ testing forms only one small part of assessing someone's strengths and needs. This is largely because IQ scores do not take into consideration information about the individual's

social, medical, educational and personal needs, nor does it account for the help and support the person might need. In recognition of this rhetoric, within clinical practice, there is an increased emphasis on the importance of adaptive and social functioning behaviour assessments rather than relying on IQ alone.

Although the concept of adaptive and social functioning is very broad it relates to the person's performance in how they cope with day-to-day demands in life and how independent they are compared to others of a similar age and background. Social functioning is measured in areas of practical skills such as; personal care, money management, and levels of independence; social skills, such as; problem-solving and interactions with others, and conceptual skills such as; planning, organising and sequencing, and understanding abstract concepts, such as time-telling. Adaptive functioning is defined in both the American Association on Mental Retardation (Luckasson *et al.*, 2002) and Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). The latter adopted a definition criterion of having at least two impairments from daily living skills or social intelligence.

As a result, learning disability services within the United Kingdom have veered away from formal IQ testing for most individuals and have swayed towards adopting the Department of Health's Valuing People report (2001) and the British Psychological Society (2015) definitions. Both descriptions clearly defined learning disability as having severe deficits in three core criteria, being:

- a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

All three areas must be present to achieve a diagnosis of learning disability.

This definition is now embedded in mental health and mental capacity legislation in the United Kingdom, thereby recognising the importance of a diagnosis in assisting in the provision of appropriate support and interventions that are aimed at benefiting the person's ability to function and their quality of life.

Traditionally, in the United Kingdom, two categories of learning disability have been favoured but more recently the Department of Health (2001) has advocated that four categories should be used: mild, moderate, severe and profound, and thus reflecting the categorisations in classification and diagnostic manuals.

People who have a mild learning disability equate to around 85 percent of the learning disability population (American Psychiatric Association, 2000). Individuals with a mild learning disability are usually able to hold a conversation and communicate most of their needs and wishes, although they may need some support to understand abstract or complex ideas (British Institute of Learning Disabilities, 2016). People are often independent in caring for themselves and doing many everyday tasks and have some basic reading and writing skills (Bond and Hurst, 2010; Scuccimarra and Speece, 1990), while others may require extra support, ranging from supported independent living with staff visiting intermittently, to fully staffed group homes (McConkey, 2007). They maintain friendships (Emerson and McVilly, 2004; Knox and Hickson, 2001) and many have committed intimate relationships (Yacoub and Hall, 2009). With adequate supports, some marry and have children (Llewellyn *et al.*, 2010; Carr and O'Reilly, 2007).

## **2.4. The prevalence of learning disability**

There is no definitive record of the number of PWLD in England as no one Government department collects comprehensive information on the presence of learning disabilities in the population and learning disabilities is not recorded in

the decennial Census of the United Kingdom population (Public Health England, 2016).

Based on estimates obtained by combining information collected by Government departments on the presence of learning disabilities among people using particular services Public Health England (PHE) estimate the overall population of PWLD to be 1,068,000 (Public Health England, 2013). This figure includes 900,900 adults. However, Emerson and Hatton (2004) predicted demographic changes in the general population would lead to an increase in the number of adults with a learning disability. They predicated factors such as increased survival rates among young people with severe and complex disabilities, reduced mortality amongst older adults with a learning disability and the increase in proportion of younger English adults who belong to South Asian ethnic minority community (where prevalence rates are higher) will contribute to an increase in prevalence of this population group (Public Health England, 2013).

A more recent update was published in November 2016 by Public Health England (Public Health England, 2016), who once again combined information collected by Government departments on the presence of learning disabilities among people using particular services, overall population predictions for England, and the results of epidemiological research. The overall population estimations for England and the results of epidemiological research gave an estimate that in England in 2015 there were 1,087,100 PWLD, of whom 930,400 were adults over the age of eighteen, equating to 2-3 percent of the general population. An increase of 980,300 in just two years (Public Health England, 2016).

Taking these latest figures into account, Public Health England (2016) estimated the total number of adults with a learning disability (defined as people aged 20 and over) will increase by 14 percent by 2021.

However, out of the twenty people in every thousand with learning disabilities, only five of these people are known and supported by the local health and social services. The rest are living independently with no additional support.

## **2.5. History of learning disability.**

It was as far back as 400 BC when Hippocrates attempted to separate superstition and religion from medicine by systematising the belief that a deficiency in or an excess of one of the four essential bodily fluids, or humours (blood, yellow bile, black bile, and phlegm) were responsible for physical and mental illness. Hippocrates identified that the brain allowed us to enjoy delights and laughter. In the same way when the brain is not healthy, it became mad and delirious. (Fabre,1997).

Historically, the care of PWLD involved segregating them from the rest of society and confining them to institutions, along with the perceived 'madmen' and 'social deviants'. Poverty, madness, disability, and criminality were considered to be God-given changeables or a form of demonic state and were therefore untreatable.

The origins of psychiatric services in England date back to 1247 when a monastic priory was founded in the city of London on the site where Liverpool Street station now stands. This priory provided shelter for the sick and infirm and from 1330 onwards was referred to as a hospital.

Foucault (1961) suggested society saw madness as being related to anti-natural animality, with the general population seeing madness as bestial and therefore justified treating the madman as a beast. This view then led to the acceptability that these individuals could not be bound by human laws and so must be confined. This observation was also recorded by Yates *et al.* (2008) who reported devalued groups, including PWLD, were cast into negative roles such as; subhuman, an object of dread, or treated like an eternal child. By the eighteenth century, the theory of animal spirits possessing these individuals



was being replaced by the theory that tension in nerve fibres led to disabling conditions (Foucault, 1961), but this alternative view still did not detract from continued confinement and institutionalisation of the so-called defective.

Foucault (1961) perceived the need for confinement, a theme that returns throughout his work, was based on a series of social and economic measures. These measures, he argued, are not legitimated because of the person's need for medical attention or out of humanitarian concern but because the power of the state felt individuals needed to be controlled and separated from 'normal' society: only by controlling the abnormal could the 'normal' exist.

Darwinism and eugenics were influential philosophies in the 1800's within the institutional care regime which, together with an increase in the medical professions power, led to policies that continued to segregate particular groups from society.

Social Darwinists advocated that social engineering would do away with or weaken the effects of nature's shaping forces. The result, they believed, would be uncontrolled breeding and weakening of the genetic pool, resulting in a deterioration of the human race and swamping of the higher types within society. Eugenicists took these ideas further and suggested that the 'degenerate' or 'defective' should not be allowed to breed or interbreed as their offspring would degrade the quality of the human race (Open University, 2010). This idea flourished well into the twentieth century and was supported by powerful individuals such as Winston Churchill who was a proponent of forcible sterilisation (Ponting, 1992).

By the beginning of the nineteenth-century psychiatrists and historians were starting to condemn confinement (Foucault, 1961). The age of positivism claimed to be the first to free the 'mad' from an association with criminals, separating these individuals from other social ills to become a special category of their own. PWLD are not a homogenous group. As Oliver and Barton (2000)

pointed out assumed heterogeneity does not allow impairments to rise to a diverse array of symptoms or disease specific trajectories.

Nevertheless, a new language started to emerge, categorised by scientific terms, with designated conditions labelled by the moral standards of the time and which overlooked individual diversity. People were classified with newly emerging medical conditions with four diagnostic criteria of idiot, imbecile, feeble-minded, and moral defective (UK Mental Deficiency Act, 1913). Institutional care was considered, in itself, to be curative and therapeutic with institutional treatment regimens and segregation believed to contribute to some kind of cure. Oliver (1998) explained this model of cataloguing people into medical models, with treatment and cures placed the individual into a sick role. People with incurable conditions were classified as sick. This led to guided attempts to cure impairments or to restore 'normal' bodily functioning which resulted in a perception of deviancy. The list of twisted denigration labels is dehumanising for PWLD and itself is a testament to the failures of services and society in relation to disability at this time (Day, 2007). Oliver (1998) argued that this labelling and categorising allowed disabled people to be treated abstractly and somehow distant from the human race with the crucial question of the causes of disability being fudged rather than clarified. He believed a medically pragmatist view contributed to socially created disabilities with industrial societies producing disability as a medical model requiring medical interventions and as a social problem requiring social provision.

Within this pragmatic philosophy, psychiatry assumed priority for the first time. Psychiatrists could confine themselves in positivism, converging with Freud, who turned the doctor into all the powers of the asylum. Observation, science, and judgement became the authority, with those in charge of the asylum looking at behaviour and deciding what was good, bad and abnormal.

With the influence of Freud, psychoanalysis and behaviourism dominated the theories in the 1950's. Whilst psychanalysis focused on understanding the unconscious motivations that drove behaviour, behaviourists studied the

conditioning processes that produced behaviour. Skinner (1957) attempted to provide behavioural explanations for a broad range of cognitive phenomena. He concluded when a particular stimulus-response pattern was reinforced, an individual would be conditioned to respond. By the 1960's a 'third wave' of psychology began to develop in the form of humanistic psychology. This theory focused on the individual's potential and stressed the importance of growth and self-actualisation with a fundamental belief that individuals were innately good (Cherry, 2010). However, from a positivist's perspective, this humanistic paradigm was viewed as being subjective with no accurate way to measure or quantify the qualities of self-actualisation.

Some of the emerging philosophies and principles of care were embodied in policy statements. By the end of the Second World War, a set of research ethical principles for human experimentation was developed in the form of The Nuremberg Code, 1947 (Shutter, 1997). The Code laid down ten standards for physicians carrying out experiments on human subjects to conform to. The standards included avoiding all unnecessary physical and mental suffering and a need to gain essential voluntary consent from the participant being studied.

In 1949, two years after the Nuremberg Code, Dr Antonio Egas Moniz was awarded the Noble Prize for Medicine and Physiology in recognition of his creation of the prefrontal lobotomy. Despite these experimental theories being based on scant evidence and the fact that evaluation studies, such as the Columbia-Greystone Project, 1947 (Finger, 1994) failed to evidence the positive effects of this procedure, frontal lobotomies were still being performed on patients as late as 1951 (Mettler, 1949). Under the Nuremberg Code such experiments were justified as they were perceived as yielding fruitful results for the good of society and were portrayed as a means to control 'undesirable' behaviour (Sabbatini, 1997).

PWLD were tested, counted, observed, analysed, described and frequently pathologised but they were never asked their views (Walmsley, 2001). Bowling

(2002) also debates the appropriateness of traditional scientific methods for the study of human life, given its complexity and the nature of individual behaviour.

It was not until 1948, with the formation of the NHS, that the term mental handicap was first used and then only in 1959 was a distinction made between mental handicap and mental health (Holland, 2011). The socially constructed term mental handicap continued to semantically construct barriers and was still aligned with mental illness. This label was abandoned for the term learning disability following the publication of the NHS and Community Care Act in 1990 (Office of Public Sector Information, 1990) with further widespread adoption through the 1990's.

Other terms that have been used include intellectual and developmental disabilities, both of which are used internationally but are not commonly used in the United Kingdom, although Barnes (1991) argued that any disability is a social construct which oppresses people with impairments, this linguistic change encouraged an affiliation to disability studies and inclusion within emancipatory research (Walmsley, 2001).

The process of de-institutionalisation started in the 1980's and PWLD began to move from institutional to community-based services (Fahey *et al.*, 2010; Emerson and Hatton, 1998). This change was in direct recognition that PWLD had the same rights as the rest of society and principles of citizenship, inclusion, and access to community-based services started to be embraced. This process of de-institutionalisation originated in Scandinavia and was referred to as 'normalisation'. It advocated integration into mainstream society, thus moving away from a segregation and deficiency model (Nirje, 1970; 1969). It was further popularised in the United States by Wolfensberger (1980a; 1980b; 1989) who argued that PWLD were seen as deviant by society, leading to stigmatisation and social devaluation. This work developed and provided the impetus in closing many large institutions and moving to community-based services (Towell, 1982) and has continued until the current day and is, as yet, incomplete. In 2016, the last standalone learning disability hospital in England

was absorbed into a mental health trust, although the planned closure of this hospital site may not be completed until 2021 (Parkin, *et al.*, 2018).

The shift to community services and a predominantly social model of care, has brought about considerable advantage in terms of integration of PWLD into mainstream society. Signposts for Success (Department of Health, 1998) was influential in promoting access for PWLD to generic health services. This was closely followed by the United Kingdom's Government white paper Valuing People (2001), the first Government white paper to be published for PWLD in thirty years. The papers action plan set a benchmark of initiatives that would pave the way for positive changes for PWLD, as well as their families and carers. Over the following years the impetus to develop policies that improve the lives for PWLD has continued resulting in a wealth of documentation that has influenced health equalities and moulded social inclusion principles (British Medical Association, 2011; Department of Health, 2009, 2000, 2011, 2012, 2014; House of Commons, 2009; Mansell, 2007a, 2007b; Disability Rights Commission, 2006; Mencap, 2004, 2007).

The Government and NHS England have continued to be committed to reducing health inequalities for PWLD and have established national programmes to improve treatment and health outcomes. In June 2015, NHS England announced a three-year national review of premature deaths of PWLD. Led by the University of Bristol, the National Learning Disability Mortality Review (LeDeR) Programme aimed to improve the quality of health and social care for PWLD through retrospective reviews of their deaths (NHS England, 2015). In the 2016-17 LeDeR's annual report (University of Bristol, 2017) it was reported that 13 percent of the reviews undertaken found that the person's health had been adversely affected by factors such as delays in treatment, organisational dysfunction and gaps in service provision. This annual report set out nine national recommendations, including mandatory learning disability awareness training. Health Education England (HEE) is currently producing eLearning materials to support Tier 1 learning disability awareness training. This free online training will to be available to all staff by 2019 (Parkin, *et al.*, 2018).

In 2011, a BBC's Panorama programme exposed the abuse of PWLD in in-patient care. The broadcast of this programme was the catalyst for fundamental change in learning disability policy and practice. The programme spurred further inspections of 150 hospitals and care homes for PWLD by the Care Quality Commission. These inspections identified poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint. As a direct response, the Department of Health (2012) published a report that pledged PWLD inappropriately placed in hospital would be moved to community-based support as quickly as possible.

Three years later, the National Audit Office (2015) published a report that suggested the Government had underestimated the complexity and level of challenge in meeting the commitments in its previous pledge, and as a consequence, the goal to move PWLD out of hospital by 2014 had not been met.

In an attempt to rectify this lack of progress, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS), published Building the Right Support (NHS England, 2015) which advocated further development of community services and the closure of inpatient facilities for PWLD and/or autism. The Government's Mandate to the NHS 2018-19 went one step further, setting an objective of achieving 35-50 percent bed reduction by March 2019.

The subsequent enquiry following the Winterbourne View exposure not only raised many concerns about the care of PWLD but also raised alarms over prescribing practices of antipsychotic and antidepressant medication within this cohort. As discussed in the introduction of this chapter, NHS England (2016) estimated that up to 35,000 PWLD are prescribed psychotropic medication without appropriate clinical justification. The Learning Disabilities Census (Health and Social Care Information Centre, 2015) raised further concerns after finding 72 percent of patients with learning disability, in hospital, had received antipsychotic medication. Similarly, in 2016, the Care Quality Commission's

Survey of Medication for detained patients with a learning disability (CQC, 2016) found 86 percent of inpatients were prescribed antipsychotics drugs on a regular basis, with more than half of individuals not having a diagnosis of a disorder that the drug was intended for.

In a response to these concerns, a variety of professionals and organisations, including NHS England, Royal College of General Practitioners, Royal Pharmaceutical Society, Royal College of Psychiatry, British Psychological Society and Royal College of Nursing (NHS England, 2016) signed up to the Stopping Over-Medication of People with a Learning Disability (STOMPLD) campaign. The campaign adapted key messages from NICE guideline (2015), with the aim to support and encourage doctors to review prescriptions of PWLD on their patient list and ensure that psychotropic drugs are only continued to be prescribed where the person poses a severe risk to the safety of themselves and/or others and all other alternatives have been exhausted.

In addition, from June 2016, the Department of Health have published independently assured ratings of the quality of healthcare offered to PWLD in all Clinical Commissioning Group areas, to highlight variations and to allow rapid action to be taken when improvement is needed (Parkin, 2016).

## **2.6. Mental illness**

As with learning disabilities, the classification of mental disorders is mainly categorised by two widely established systems that have achieved widespread acceptance in psychiatry. The International Classification of Disease (ICD-10), produced by the World Health Organisation (1992) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), produced by the American Psychiatric Association (2000). The DSM began in 1952 and reflected psychodynamic opinions of the time. Both publications list categories of disorders with revised codes that offer a broad comparison, but differences between the two systems continue to exist despite unifying attempts.

Psychiatry has evolved its lexicon over the years. The term psychosis was initially introduced by Ernst Feuchtersleben in 1845 (Department of Psychiatry, 1995) but the meaning of this term has changed with time.

Literature on the definition or categorisation of mental disorders also differs, with one extreme arguing that it is a matter of value judgments that depicts what is normal (The British Psychological Society, 2016), while another paper proposes that it is entirely objective and scientific (Berrios, 1999). Other views advocate that the concept refers to a fuzzy model that can never be precisely defined or that the definition will always involve a mixture of scientific facts (Perring, 2005). The British Psychological Society (2013) supports the view that many of the issues in relation to psychiatric diagnosis have their origins in physical disease models and medical classifications, with terms such as symptoms, mental illness or psychiatric disease wrongly applying to the realms of thoughts, feelings and behaviours. It should also be recognised that lay concepts of mental disorder vary considerably across different cultures and countries (Giosan *et al.*, 2001). The World Health Organisation reiterates this view within the national surveys report, by identifying that there is no single consensus on the definition of mental disorder or illness and that the phrasing used depends on the social, cultural, economic and legal context in different circumstances and in different societies (WHO, 2005).

When describing a mental disorder or illness different terminology is often used. Psychosis is a syndrome or group of symptoms, whereas schizophrenia is a mental illness that causes psychosis. So, for example, individuals diagnosed with schizophrenia may have symptoms of psychosis but not everyone with psychosis will be diagnosed with schizophrenia. Types of psychotic disorders include schizophrenia, bipolar affective disorder, schizoaffective disorder, schizophreniform disorder, delusional disorder, substance-induced psychotic disorder and paraphrenia. As this study aims to explore the lived experience of PWLD who have experienced this range of mental illnesses the term psychosis will be used to incorporate all symptom experiences.



Broadly speaking, psychosis means a loss of contact with reality; it is a symptom of mental illness rather than a medical condition in its own right. Generally, there are two types of psychiatric disorder that produce psychotic symptoms: schizophrenia and mood disorders, such as bipolar disorder.

Psychotic symptoms can be separated out and given specific descriptions. The classic signs of psychosis include hallucinations and delusions; disorganised thought, speech, or behaviour; disordered thinking; and catatonia. Core clinical symptoms are usually divided into positive and negative symptoms. Positive symptoms because they add experiences, such as hallucinations and delusions and negative symptoms, so called because something is reduced, for example, a lack of drive, emotional apathy, poverty of speech, social withdrawal or self-neglect (NICE, 2014). Hallucinations (being a perception in the absence of any stimulus) usually present as hearing voices (auditory hallucinations), strange sensations or unexplainable feelings, such as seeing glimpses of objects or people that are not there or distortions. Whereas, delusions (being fixed or falsely held beliefs) usually present as a belief that external forces are controlling thoughts, feelings and behaviours; a belief that trivial remarks, events or objects have personal meaning or significance and; thinking they have special powers, are on a special mission, or are being spoken to by God.

Depending on the cause, psychosis can come on quickly or slowly. A slow onset, which is also called the prodromal phase, usually starts with the initial symptoms of feelings of suspicion, distorted perceptions, depression and suicidal feelings, obsessive thinking and sleep problems. This stage is often not recognised by the patient or their family and friends (NHS England, 2015).

Psychosis is a devastating illness affecting 3.4 percent of the population over a lifetime (Perälä, 2007), with 80 percent of individuals relapsing within five years after the first episode (Palmier- Claus, *et al.*, 2012). The British Psychological Society (2014) suggest that up to ten percent of people, will at some point in their life, hear a voice talking to them when there is no-one there. It is also

known that people with psychosis have poor physical health and die much younger than the general population, even after allowing for suicide. One study (Laursen, 2011) estimated a reduction of 18.7 years and 16.3 years in men and woman with schizophrenia, respectively.

Early diagnosis of psychosis can improve long-term outcomes with the association between longer periods of untreated psychosis and poorer outcomes being firmly established in the literature and clinical practice. People who do not access effective treatment quickly are far more likely to experience poor physical health, lower levels of social functioning and poorer occupational and educational outcomes (Marshall *et al.*, 2005). Early intervention is not a novel idea. Claims of its benefit date back a few hundred years (Warner, 2005). More recent studies in the 1980's (Johnstone *et al.*, 1986; Cameron, 1938) confirmed the prognostic influence of length of untreated psychosis on outcome, with the greatest impact on illness being made during the period of neuronal and psychosocial plasticity (Birchwood *et al.*, 1998).

## **2.7. Early intervention**

Early intervention can be a confusing term as there is no etiopathological basis for diagnosing psychotic disorders; it can only be diagnosed by symptoms or combinations of symptoms. In addition, there are no known malleable causal risk factors which predict the onset of psychotic disorder with any specificity. Thus, it seems that primary prevention is currently out of reach. Early intervention, therefore, really means early secondary prevention (McGorry *et al.*, 2008).

Early or first-episode psychosis refers to when a person first shows signs of beginning to lose contact with reality or the first time a person experiences a combination of symptoms known as psychosis. Acting quickly to connect a

person with the right treatment during early psychosis can be life-changing and radically alter that person's future.

Determining exactly when the first episode of psychosis begins can be hard, but these signs and symptoms strongly indicate an episode of psychosis:

- Hearing, seeing, tasting or believing things that others don't
- Persistent unusual thoughts or beliefs that can't be set aside regardless of what others believe
- Strong and inappropriate emotions or no emotions at all
- Withdrawing from family or friends
- A sudden decline in self-care
- Trouble thinking clearly or concentrating

Early psychosis rarely starts suddenly. Usually, a person has gradual, non-specific changes in perception, thoughts, mood, with their behaviour becoming significantly altered (NICE, 2014).

In 1986 the Northwick Park study (Johnstone *et al.*, 1986) observed an association between delays to treatment and resulting disability. As beneficial empirical evidence began to emerge on the early detection of psychosis a pioneering first early detection and prodromal clinic was established in Melbourne, Australia (McGorry *et al.*, 1996), with similar services soon being replicated across the globe.

Over the past few years development of early intervention services has steadily grown, supported by two large randomised control trials from the United Kingdom (LEO trial) and Denmark (OPUS trial) (Garety *et al.*, 2006; Petersen *et al.*, 2005; Craig *et al.*, 2004). A meta-analysis from pooled data of three trials showed that early intervention services significantly reduce the risk of a second relapse (Álvarez-Jiménez *et al.*, 2009) with the message from the OPUS trial indicating once the early intervention grip is relaxed clinical gains are lost; interventions are therefore effective only as long as actively implemented.

McCrone *et al.*, (2010), described how the London School of Economics (LSE) and King's College London had demonstrated that by providing an early intervention service approach, rather than standard mental health care, increased clinical and social benefits. The study estimated that for one cohort of patients with psychosis, the United Kingdom could save £40 million per year in the short term, £33 million in the medium term, with £18 million savings in the long term. Apart from reducing traumatic hospitalisation in crisis, maintaining individuals in employment, improving access to treatments and reducing the burden for carers, the research also identified a reduction in the frequency and severity of relapses with faster recovery for individuals.

The Mental Health Strategy, No Health Without Mental Health, was first published in February 2011 (HM Government, 2011) and replaced the National Service Framework (Department of Health, 1999) by consolidating the coalition Government's new approach to direction setting in mental health services. The strategy set out six objectives to improve mental health outcomes with Early Intervention services (EI), across all age groups being a key priority, a theme that has continued within the newly launched Five Year Plan for Mental Health (Mental Health Taskforce, 2016).

Teaching individuals to recognise the early symptoms of an episode of a recurrent health problem, and to seek early treatment and limit harm, is a well-established secondary prevention strategy for medical disorders such as myocardial infarction (Morris, 2003). This early warning signs approach to prevent relapse is just as important in psychotic illness, as each relapse may result in the growth of residual symptoms. Various authors have reported initial subtle changes in the individual's thoughts, affect and behaviour that precedes the development of florid psychosis (Jorgensen, 1998; Birchwood *et al.*, 1989; Herz and Melville, 1980). These changes generally occur in a predictable order, with non-psychotic phenomena occurring in the early stages followed by increasing levels of emotional disturbances (Docherty *et al.*, 1978), with a three to four-week window between the onset of the early signs of relapse and the development of a full psychotic episode (Biocina and Agius, 2011).

These early subtle symptoms are often referred to as the psychotic prodromal stage, illustrated in figure 1.

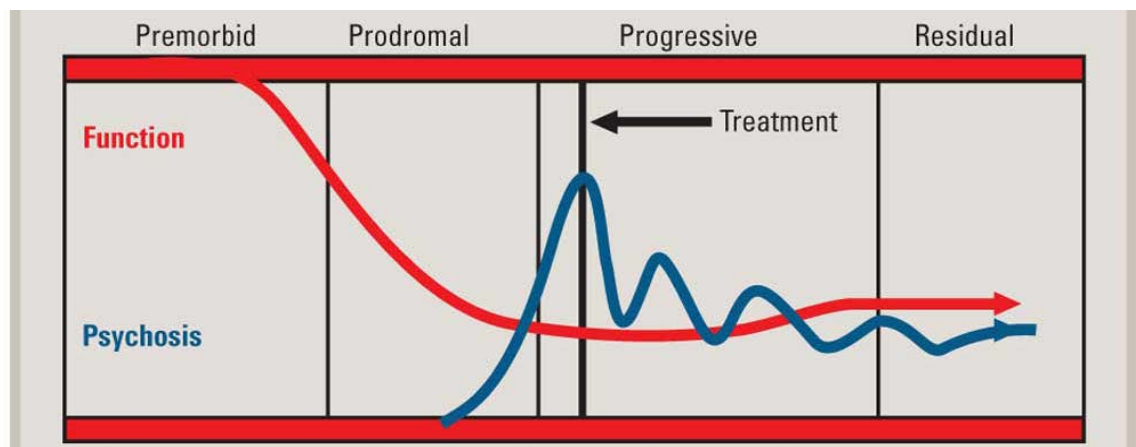


Figure 1 (Sourced: Emotion in Schizophrenia: No Treatment for Negative Symptoms?, 2016)

Prospective studies have shown that psychotic relapse can be predicted with a sensitivity of 50-79 percent and a specificity of 75 to 81 percent when standard measures of neurotic or dysphoric symptoms are combined with those of low-level psychotic symptoms, with prediction becoming more accurate when individuals have their own baseline recorded (Jorgenson, 1998; Birchwood *et al.*, 1989; Subotnik and Neuchterlein, 1988).

A survey conducted by the National Alliance on Mental Health (2011) found approximately 40 percent of individuals who experienced psychosis said initial insight came from recognising symptoms themselves. However, approximately 20 percent of individuals who experienced psychosis felt that no one helped when the onset of symptoms occurred. Only a small percentage of accredited health care providers helped to recognise symptoms, suggesting that providers become involved with the individual much later in the illness process.

It is for these reasons that research attention has been directed towards identifying each individual's relapse signature or their own unique pattern of

early warning signs (Eisner *et al.*, 2014; Smith, 2010; Judge *et al.*, 2008; Lam, 2000; Falloon, 1996). Birchwood, Spencer and McGovern (2000) took this research further and developed a detailed system for the identification of early warning signs. Max Birchwood and colleagues (IRIS, 2000) re-published the IRIS Early Intervention Guidelines which offered a table of 58 signs of early relapse in psychosis, sub-divided into thoughts, feelings and behaviours categories. They recommended using a card-sort exercise with validated psychotic symptoms written on them to aid individuals to identify their own signs of relapse.

This sort-card exercise was designed to be used in two stages. In the first stage, the person sorts through the cards and chooses the cards that they identify as symptoms they have personally experienced. In the second stage, the person arranges the selected cards into a timeline, with the earliest symptom placed first followed by other symptoms in chronological order: with the symptoms that are closest to the relapse being placed last. The selected symptoms are then used to develop an individual relapse signature and relapse drill or action plan.

## **2.8. Learning disability and mental illness**

Until as recently as the 1980s, it was still believed that PWLD did not have the cognitive capacity to experience mental illness. The belief that PWLD are not susceptible to mental illness is no longer valid (Raghavan and Patel, 2005; Hardy *et al.*, 2004) as it is now known that they do experience the same mental ill-health as adults without such disability and that they are probably more vulnerable. Increased risks are associated with social, psychological, economic, emotional and biomedical factors (Burke, 2014). Many PWLD live in poverty, have few friends and have additional long-term health problems, all of which are associated with mental health problems (Hardy and Woodward, 2010; Martorell and Tsakanikos, 2008).

Much of the epidemiology of mental health problems in adults with learning disabilities is still unknown. Research suggests the prevalence of psychiatric disorders is significantly higher among adults with learning disabilities compared to general population (Cooper *et al.*, 2007; Singleton *et al.*, 2000). The figures, however, vary enormously, differing from ten percent to as high as 60 percent. (NICE, 2013; Bailey, 2007; Whitaker and Read, 2005; Wallace, 2002; Deb *et al.*, 2001; Cooper *et al.*, 2007; Lund, 1985; Corbett, 1979). Most of the research has been carried out on bias samples using inadequate methods of identification and few results can be generalised (Smiley, 2005) which may explain the significant difference in the literature. Differences may also be due to the lack of appropriate diagnostic criteria, the methods used for assessing psychopathology, and the lack of definition in terminology which can include mental illness, mental disorder, psychiatric illness, psychiatric disorder and behavioural disorder. Most of the prevalence studies examined individuals from institutional settings or were based on case-note scrutiny, with direct patient interviews seldom used. Nevertheless, from an overview of the literature it is reasonable to assume that between 20 and 25 percent of people with mild to moderate learning disabilities will experience mental health problems at some time of their lives (Grey *et al.*, 2010) with individuals having intricate needs (Raghavan *et al.*, 2004).

Studies have specifically reported the prevalence of schizophrenia to be as high as 35 percent, compared with 1 percent for the general population (Burke, 2014; Dooby *et al.*, 1998). Furthermore, between 70 percent and 85 percent of PWLD referred for psychiatric assessment were found to have one or more untreated, undertreated, or undiagnosed co-occurring non-neuropsychiatric medical problem influencing mental health and behaviour (Ryan and Sunada, 1997). The Count Us in Inquiry (Foundation for People with Learning Disabilities, 2002) also identified diagnostic overshadowing, carers and professionals lack of knowledge, not being listened to, referrals passed from service to service, and communication difficulties as some of the key themes that hindered accurate diagnosis.

Even at the best of times, the use of a diagnostic criteria for mental health disorders in the general population has been questioned (Raghavan and Patel, 2005). There is debate on the negatives of approaching mental distress as a disorder within a medical model (Dillon & May, 2003). By applying a diagnostic criterion there is a tendency to remove the personal experience (Johnstone, 2012; Martindale, 2012) and can turn 'people with problems' into 'patients with illnesses' (Johnstone, 2013). This adoption of a social-constructed stigmatising approach is known as labelling theory (Scheff, 1966; Goffman, 1959; Durkheim, 1952).

Although it is recognised PWLD are people first, sometimes additional considerations and terms, or labels, can be helpful as a means to access appropriate care and support (NICE, 2017). In being able to apply a label of mental illness may frame the clinical approach, aid the person to seek help, and allow for individual understanding, resulting in access to treatment and recovery (Pitt *et al.*, 2009; Cohen, 2003). The sooner a diagnosis is confirmed the sooner meaningful psychoeducation and detailed discussions around prognosis and relapse can begin (Hobbs *et al.*, 2017). To avoid seeing a person as a diagnostic classification and not as an individual, it is paramount that individual symptoms and lived experiences are identified and validated. As Strauss (1989) suggests, individuals should have a relationship with their disorder that influences course and outcome.

The essential feature of any mental illness is a clinically recognisable set of symptoms or behaviours, usually associated with distress and interference in personal functioning (Moss, 2012), but the identification and correct diagnosis of mental health problems in learning disabled adults is complex and can be highly challenging even for the most experienced clinicians. In recognition that psychiatric disorders can present differently in PWLD, and that the more generic diagnostic manuals have limited application, the Royal College of Psychiatrists (2001) developed the DC-LD (Diagnostic Criteria for Psychiatric Disorders for



Use with Adults with Learning Disability/Mental Retardation), a diagnostic criterion to use with PWLD.

To help identify mental health symptoms for PWLD, the ideal would be to adopt the same process used within the general population but most assessment tools for psychiatric disorders are not validated for PWLD. The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) was developed in the early 1980's and included a psychopathology self-reporting assessment for PWLD (Matson *et al.*, 1984) but independent studies have shown it maps poorly to diagnostic criteria and correlation between the informant and the self-reported version was unimpressive (Watson *et al.*, 1988) and is no longer in publication. Other validated tools for PWLD include the Aberrant Behaviour Checklist (Aman *et al.*, 1985) The Emotional Rating Scale for Developmental Disabilities (Feinstein *et al.*, 1988), and the Reiss Screen for Maladaptive Behaviour (Reiss, 1988) but these are screening tools rather than a diagnostic instrument.

Other tools are designed to identify anxiety and depression rather than psychosis (Hamilton, 1969; Beck *et al.*, 1961) but are not specifically designed to use with PWLD. The Glasgow Depression Scale (Cuthill, 2003) and the Glasgow Anxiety Scale (Mindham and Espie, 2003) are both self-reporting tools that have specifically been adapted for PWLD, but once again do not include the symptomology of psychosis. The Learning Disability Cardinal Needs Schedule (LDCNS) was adapted from the Cardinal Needs Schedule (Raghavan *et al.*, 2004; Raghavan, 2000) but the primary use of this tool is to identify the needs of individuals who had already received a diagnosis.

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities or PAS-ADD Mini and the PAS-ADD Checklist (Moss *et al.*, 1998) and the Psychotic Symptoms Rating Scale (Haddock *et al.*, 1999) are reported to be diagnostic tools but rely on carer or clinician reporting only; the person themselves is never consulted about their symptoms. The PAS-ADD interview has reported relatively good diagnostic accuracy on the anxiety disorders

subscale. However, the Guideline Committee members for the NICE guidelines on mental health problems in PWLD (NICE, 2016) found that the neurotic, depression and schizophrenia symptoms subscales had little supporting evidence and considered it to be essentially a screening instrument and not suitable for assessment purposes.

More recently NICE (2017) has recommended that mental health screens should be included in the annual health checks for PWLD. One of the quality statements recommends that individuals who are identified as requiring further mental health assessment should be referred to a professional with expertise in mental health problems in PWLD, but the statement does not specify what constitutes an assessment nor does it stipulate the need for self-reporting of symptoms. This continued reliance on signs rather than symptoms (Woodward and Halls, 2009) and third-party reporting may stem from a perception that obtaining a lived experience is difficult as many PWLD have communication difficulties, suggestibility, poor recall, and acquiescence.

However, several large-scale surveys have sought the opinions of people with learning disabilities regarding their physical health experiences (Emerson *et al.*, 2004; Band, 1998) but subjective reporting of psychotic symptoms by PWLD is difficult to locate within the literature (Varghese and Banerjee, 2010; Cookson and Dickson, 2009). Evidence from groups without a learning disability, such as the Hearing Voice Network, suggest that finding a voice to articulate experiences can have a positive and powerful effect. Although it is recognised that the process can be difficult to cope with, sharing the lived experience is reported to be positively life-changing (The British Psychological Society, 2016).

Instead, for PWLD, there is a reliance on carers and relatives to give a corroborative history, together with direct observations of the person's behaviour and functioning in different settings to form the diagnosis (Myers, 2016; Hassiotis and Turk, 2012; Bradley *et al.*, 2011; Varghese and Banerjee, 2010; Raghavan and Patel, 2005). This method of assessment is not always

accurate, even for people without a learning disability, as identified within the National Alliance on Mental Health (2011) survey. The survey highlighted carers do not reliably recognise early psychotic symptomology and often do not realise the significance because of a lack of understanding and knowledge of psychotic problems.

Although people with a mild learning disability may be able to report their thoughts, feelings and emotions to another person, it can be problematic for PWLD to clearly describe first-rank symptoms. (Raghavan and Patel, 2005). Furthermore, positive symptoms seen in the general population are uncommonly reported in PWLD, probably because it is difficult to elicit disorders of thought or perceptions as there is no objective basis in reality (Royal College of Psychiatry, 2001).

Nearly two decades ago, both Signposts to Success (Department of Health, 1998) and The Mansell Report (Department of Health, 1993), advocated that meeting the mental health needs of PWLD should be highly individualised. Deb *et al.*, (2001) suggested that diagnostic interviews should involve the person themselves with the use of visual aids and reasonable adjustments, but they did not suggest a tool to facilitate this. Additional references for reasonable adjustments to be made within the psychiatric interview include acknowledgement of the need to use open-ended questions and an awareness of the illusion of linguistic competence (Raghavan and Patel, 2005; Chaplin and Flynn, 2000) but none suggest itemising psychotic symptoms with easy read information to ensure accurate reporting; similar to the sort-cards used within Birchwood's (1995) research.

Marshall (2013) developed a Clinical Outcomes measure, incorporating symbols evaluated by PWLD, to ascertain levels of distress which was sensitive in the evaluation of depression, anxiety and low self-esteem but did not include symptoms of psychosis.

There are a number of information leaflets that have been produced that provide accessible information on psychosis (2gether NHs Foundation Trust, 2016; Leicestershire Partnership Trust, 2016; Hampshire Partnership NHS Trust, 2008) but obviously, none of these can be used for assessment purposes.

## **2.9 Current practice for PWLD with mental health difficulties**

It is evident from the literature that PWLD have limited resources to recognise and articulate their own psychotic symptoms. In addition, there is no published literature on the use of Birchwood's (1995) Early Intervention sort-cards being used within the learning-disabled population, nor is there any other evidence that any form of Easy Read or accessible information is available to assist PWLD to identify their psychotic symptoms and lived experiences. This finding is also highlighted within NICE guideline (NICE, 2016). The Guidance Committee recognised the dearth of available published research in this area, so they conducted focus groups with PWLD in an attempt to collect anecdotal evidence to support the publication. However, the focus groups were also unable to identify any further guidance and confirmed a lack of accessible information was a significant problem.

The mental health of PWLD has been previously neglected outside learning disability services (Adshead, *et al.*, 2015) with universal mental health services often denying parity of access to this population group (Beecham, *et al.*, 2002; Roy and Martin, 1997; Moss and Patel, 1993). Historically, learning disability services and mental health services have worked in isolation, often with different boundaries and eligibility criteria. Staff within each individual service have their own specialist skill set that would not necessarily meet the dual needs of a PWLD and additional poor mental health. This was coupled with a perception that mental health care for PWLD should fall under the responsibility of learning disability services. Mainstream psychiatrists, psychologists, senior

nurses and managers all presumed that the local clinical provision for PWLD and mental health needs was part of specialist learning disability service remit (Gravestock and Bouras, 1995).

The Department of Health (2001) advocated equity for PWLD in accessing mainstream NHS services, including the full range of mental health provision (DH, 2001). This common theme of equitable access to all health services has continued in more recent United Kingdom policy (NHS England/LGA/ADASS, 2015; NHS England, 2014; DH, 2000; 2012; 2015; NDTi, 2012; HM Government, 2011; Mansell, 2007; DH, 2006)

However, despite numerous national reports and policy initiatives over the last few years, which state that healthcare services should be for everyone, PWLD continue to be marginalised when it comes to accessing good healthcare from mainstream NHS services (Norway, 2019; de Castella, 2018; Brittle, 2004). This marginalisation is evident within clinical practice. While the label of a learning disability endows entitlement to specialised services, the reality in practice is very different. Having a right to, and actually gaining access, are two distinct issues. There continues to be disagreements about whether PWLD should be treated by mental health services or by specialist learning disability services. Moreover, people with mild learning disabilities are at particular risk of falling between the two services, with both denying that they meet eligibility criteria. (Hemmings, *et al.*, 2014; Joint Commissioning Panel for Mental Health, 2013; Foundation for People with Learning Disabilities, 2011). As a consequence, specialist learning disability services are often left to either be the sole provider of an individual's mental health care or are expected to support universal mental health services in working with the individual (de Castella, 2018; Alborz, *et al.*, 2005).

When the PWLD does access mainstream NHS services, the experience and confidence of clinicians in caring for this patient cohort is variable. Often, qualified nurses show a lack of knowledge and skills in meeting the needs of

PWLD (Adshead, 2015; van Schrojenstein, 2005). Inadequate training of mainstream clinicians has been cited as one of the reasons for poor health outcomes for PWLD (de Castella, 2018, Heslop, *et al.*, 2013; Michael and Richardson, 2008). Moreover, gaps in nursing knowledge have been recorded as a contributing factor to deaths of patients with learning disabilities. In a survey by Mencap (2010), involving 417 hospital nurses and 223 primary care nurses, a third of the respondents reported personally witnessing PWLD being treated with neglect, or lack of dignity, or receiving poor quality care.

The same themes that underpin the failures in care provision, such as poor communication, lack of training and a lack of reasonable adjustments, also fail to comply with the Equality Act, 2010 (Mencap, 2018; Mencap, 2012; HM Government, 2011; DH, 2000). It is a statutory requirement under the Equality Act, 2010 and the NHS and Social Care Act, 2008, that public sector agencies must ensure, by way of making reasonable adjustments, that they are as accessible to disabled people as to everyone else. This legal duty is anticipatory, meaning that services are required to consider, in advance, what adjustments PWLD will require. However, the results of Mencap's survey (2010) found that a third of respondents said that they had not been trained in how to make reasonable adjustments for PWLD and twenty-two percent of universities do not include making reasonable adjustments in their graduate medicine degree.

## **2.10. Augmentative and Alternative Communication (AAC)**

The term visual literacy was coined by Debes in 1969 (Avgerinou and Ericson, 1997) and refers to knowledge derived from visual aids. This idea has evolved over the years with the more recent term of Augmentative and Alternative Communication (AAC) being adopted. AAC denotes supplementing or replacing spoken communication for an individual and is particularly appropriate for those who have difficulty with receptive and expressive language due to physical, sensory or a learning disability.

In the 1980s the idea of using symbols, as a form of AAC, to support written text in education technology was established (Widgit, 2010). Within the United Kingdom there are five commonly used symbol systems; being Rebus, Blissymbols, Makaton, Picture Communication Symbols, and Widgit Symbol Set.

Rebus was developed from the American Peabody Reading Scheme with most symbols stylised with pictures that represent an object or action (Everyone Communicates, 2016), as depicted in figure 2.



Figure 2: (sourced: Everyone Communicates, 2016)

Blissymbolics were developed by Charles Bliss who was inspired by Chinese characters when he was a refugee in the Second World War. His aim was to create an easy-to-learn international auxiliary language to allow communication between different linguistic communities. He originally called his invention Semantography. Since the early 1970s Blissymbolics have been used mainly as a communication aid for people with communication and language difficulties and are particularly suitable for use by individuals without a cognitive delay who may have physical difficulties in verbal communication, such as individuals with cerebral palsy, who require a more complex vocabulary than pictorial systems (Blissymbolics, 2016).

The symbols are made up of basic shape elements, with an example seen in figure 3.

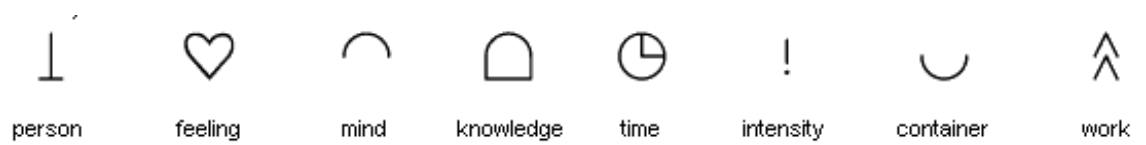


Figure 3: (Source: Blissymbolitics, 2016)

Makaton is a signing system, based on British Sign Language that has additional symbols that are taken from the Rebus symbol glossary (see figure 4). It was developed by Margaret Walker, a Speech and Language Therapist working in a long stay hospital for adults with learning disabilities (Ford, 2006). Although the symbols are clear to understand the more complex the issue the more abstract the symbols become.



Figure 4: (Sourced: Ford, 2006)

Picture Communication Symbols (PECS, 2016) originated in the United States as photocopyable files and were divided into subsections, as seen in figure 5.

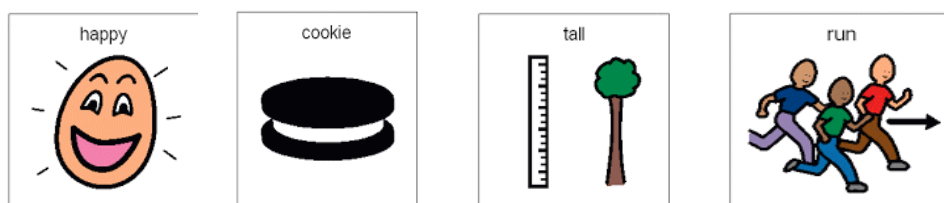


Figure 5: (Sourced: PECS, 2016)

Widgit (2010) extended the idea of Picture Communication Symbols symbol language through the creation of Widgit Symbol Set, an extensive set of symbols that illustrate words and concepts, shown in figure 6.





Figure 6: (Sourced: Widgit, 2010)

All communication involves the systematic use of symbols of some description. Research in psychology and marketing indicates that humans have a cognitive preference for picture-based, rather than text-based, information: the so-called 'picture superiority effect' (Katz *et al.*, 2006). Further research has shown visual materials have a significant impact on patient understanding (Moseley *et al.*, 2009). In Delp and Jones's (1996) study they found patients receiving information for laceration aftercare were notably more likely to read a handout when pictures were included with the text. They also found that those who received information with supported pictures had an increase of 20 percent adherence to the medical instructions, with the study suggesting pictures influenced behaviour.

Other researchers have used pictures to augment text when communicating information on cancer and HIV/AIDS. With text alone only, 14 percent of the information was remembered correctly, compared with over 80 percent when pictures were used (Houts *et al.*, 2006). In a study of individuals with low-literacy skills, who were prescribed antibiotics, it was also found pictograms were particularly useful in conveying the timing of doses, instructions on administration and course completion (Dowse and Ehlers, 2005; Mansoor and Dowse, 2003).

The results of these studies are understandable as we are exposed to symbols from an early age. In Callaghan's study, it was claimed that by three years of age children had a symbolic understanding of pictures and that they could understand that a symbol represented something outside the picture or symbol and by five years of age children could understand the link between symbol and referent (Rochat and Callaghan, 2005; Callaghan, 2000).

We are all used to some form of augmentative communication in our daily life, for example, gestures (waving goodbye) and graphic symbols such as road signs, fire assembly instructions, laundry labels and public information signs. These pictograms are figurative drawings that convey information of an analogical or figurative nature to indicate an object or to express an idea. They are used to replace written instructions expressing regulatory, mandatory, warning or prohibitory information. Although pictograms hold certain advantages for processing information there are problems related to the interpretation of intended meaning. For example, a no smoking sign shows a cigarette, but it also applies to cigars and pipes (Tijus *et al.*, 2007). Photographs can be more meaningful than symbols, but they can also be restrictive, for example, a photograph could mean a specific cup rather than drink, whereas symbols are able to convey a general concept or idea.

When some concepts are difficult to communicate with words alone authors create graphs, charts, diagrams, maps, and timelines to help communicate complex ideas and make them more concrete. These visual aids can also be a powerful tool to enhance presentations. It is recognised that pictures and symbols are not a substitute for text, or a replacement for verbal interaction and support, but when used in conjunction with written information the visual information contributes greatly to meaning and understanding.

The difficulty with augmented systems is that they are best suited to concrete terms. Concrete terms refer to objects or events that are available to the senses. Examples of concrete terms include spoon and table. These terms refer to objects we can see, hear, feel, taste or smell, their meanings are stable. Research that discusses symbols often refers to the iconicity of the symbol, with it being culturally, time and experience bound. For example, a triangle road sign with a red margin is arbitrary because it is not motivated by any aspect of a meaning, whereas a cycle lane warning road sign has an iconic image or visual relationship of a bicycle. Researchers argue the iconicity of symbols influences

understanding and acquisition (Von Tetzchner *et al.*, 2005; Mirenda, 2003; Koul and Schlosser, 2001; Fristoe and Lloyd, 1979), although there is no single ideal symbol set that has more iconic symbols than another (McClure and Rush, 2007).

Whereas, abstract terms refer to ideas or concepts that have no physical referent, for example, *justice* and *freedom*. These terms are fairly common and familiar and because we recognise them we may imagine that we understand them—but we really can't because the meanings can change between cultures and individuals. Take *beauty* as an example. The word changes meaning with different variables such perception, age, gender, and context. Symbols used to communicate an abstract concept, are often referred to as opaque symbols, such as *why*, *what*, *where*, as they have the least pictorial resemblance to what they present. They only infer a meaning from the context in which it is used, with a key symbol being used to convey a message. In a systematic review Gowland (2011) found visual aids supported understanding when they represented a concrete concept and comprehension of abstract concepts, such as emotions and time, was not enhanced through visual aids, although the pictures, or anchors, were useful to prompt descriptions of personal experiences by orienting participants to a particular time or place.

## **2.11. Augmentative and Alternative Communication (AAC) and learning disability**

The Disability Equality Act (2005) placed an emphasis on public services to actively promote equality. The Disability Discrimination Act (1995; 2005) first introduced the concept of reasonable adjustments. Reasonable adjustments refer to services operating in a slightly different way to avoid, as far as possible, disadvantaging someone with a disability, such as removing physical barriers, offering longer appointments, or providing Easy Read information. In the later amended version, The Disability Equality Act (2005) stipulated a duty on public

services to provide information in an accessible format with visual aids recommended to make comprehension easier and information more accessible.

Accessible patient information is also a feature in Government policy (Department of Health, 2000, 2001, 2008), with the core principle of enabling those with learning disabilities to have more choice and control over their lives. Furthermore, from 1<sup>st</sup> August 2016 onwards, all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard (NHS England, 2015). The standard aims to ensure people who have a disability, impairment or sensory loss, and their carers, are provided with information that they can easily read, understand and, with support, can communicate effectively with health and social care services. These policies also recognise that Easy Read information will not necessarily meet everyone's needs, advocating that services should consider other media, such as videos, talks, dramas, role-play and posters, to enhance understanding. Whichever format is used one of the guiding principles for any accessible information is to ensure the intended audience is involved in the development (Oldreive and Waight, 2014; Department of Health, 2010; Codling and Macdonald, 2004; Cardone, 1999).

Based on the premise that it is easier to process information through the visuo-motor channel (Broadley *et al.*, 1995) and that AAC can support both receptive and expressive language skills (Ronski and Sevcik, 1997) there is an array of documentation aimed at supporting services to develop Easy Read accessible information (Mencap, 2017; Total Communication, 2017; Changing Our Lives, 2013; Royal College of Speech and Language Therapist, 2013; Department of Health, 2010; Social Care Institute for Excellence, 2005) with the guidance suggesting adopting appropriate font size, avoiding jargon and acronyms, and using pictures to accompany text. A good overview of use of accessible information is given by Rodgers and Namaganda (2005) in their guidance for producing user-friendly information, with an emphasis that information should be complied by, or with PWLD.

Hurtado *et al.* (2014) asked whether Easy Read information is really easier to read and explored whether there were differences in comprehension by comparing a leaflet with pictures and text, with a picture-only version. The findings of the study suggested that all 44 participants with learning disability benefited from having a leaflet shown and read to them but that neither leaflet was more effective at making the document easier to understand. However, they did find some evidence that for the more intellectually able participants pictures were more effective at adding comprehension in the absence of text. They concluded that the generalised use of text and picture formats for all PWLD, in spite of limited evidence supporting its effectiveness, is somewhat concerning.

In a meta-narrative review Chinn and Homeyard (2016) found limited empirical evidence on accessible health information and even less on the impact of this information for PWLD in respect of health outcomes. Poncelas and Murphy (2007) found no overall benefit of symbol-based materials in their study, which tested whether a symbol-based political manifesto increased the understanding of material for PWLD. Thirty-four participants were included and randomly assigned to two groups; one received text-based information, and the other, symbol-based information with text. Overall, the results demonstrated that the addition of symbols to simplify text did not significantly improve comprehension compared to the text-only group; however, more able participants and those that had used symbols previously did show significantly improved understanding in a follow-up test. In support of these findings Codling and Macdonald's (2008) study established that by just adding a symbol to a text did not help PWLD understand, concluding that a symbol does not always convey what we think it conveys, with participants misconstruing visual supportive information.

Mirenda (2003) reviewed existing research literature on AAC and concluded that successful communication relies on an individual's preferred mode of

communication that is highly personalised. This raises an important limitation on the later studies by Poncelas and Murphy (2007); Codling and Macdonald's (2008); and Chinn and Homeyard (2016), discussed above, namely that it cannot be assumed that one particular way of presenting information will be beneficial to all of the participants. The success of the mode of presentation depends on the individual characteristics of the person coupled with their familiarity with the mode of presentation and so the likelihood of being able to demonstrate significant changes in understanding over a short period of time is small.

In contrast, many authors have developed Easy Read, or used accessible information, to support the research process, especially when examining PWLD understanding of physical health conditions (Grove *et al.*, 2009; Lewis *et al.*, 2008; Aldridge, 2007; Nind *et al.*, 2007; Burning and Steel, 2006; Pockney, 2006; Emerson *et al.*, 2005; Brewster, 2004; Booth and Booth, 2003; Goodman, 1998; Swain *et al.*, 1998; Murphy, 1997; Gray, 1994).

Other research has shown that when symbols are added to support the written word there is an increase in attention, recall, and comprehension (Madigan, 2005) and for PWLD it is argued when symbols are used alongside text there is a potential to assist approximately 60 percent by enhancing communication (BILD, 2007). Detheridge and Detheridge (2013) draw upon research in schools and colleges to affirm the contribution that symbols can make in teaching and learning for PWLD. They discussed the use of Widgit symbols to support the literacy of some PWLD, however, they noted that there is little academic research to support reported anecdotal benefits. Focusing on symbols specifically, Jones, Long, and Finlay (2007) tested whether adding symbols to written text could improve the comprehension for adults with a learning disability. Nineteen adults were asked to read four short passages of text, two of which had Widgit symbols included, and were subsequently asked questions to test comprehension. The results demonstrated that participants' comprehension scores were significantly higher for the symbolised passages

than the non-symbolised ones, suggesting a benefit for these participants in augmenting the text with symbols.

In a pilot project within the criminal justice service (Parson and Sherwood, 2015), participants felt that in using Widgeit symbols the information was made more accessible and was deemed appropriate to be used across a wide range of users. In Zentel *et al.* (2007) investigation they examined the influence of different representational formats (text, speech, symbols) on the understanding of PWLD accessing information online. The findings suggested that the text plus symbol plus spoken version produced the highest understanding and recognition scores, with text plus speech coming in second place. In a second study, 47 participants with learning disability took part and the authors reported similar findings in that by enriching written text with both symbols and spoken text learning was enhanced.

As already discussed in 2.10, the quality of research in this area is generally low with limited sample sizes and a lack of detail in the reporting of methods, which makes it difficult to judge how some of the conclusions were arrived at. Nevertheless, whatever augmented media is used the key message from the literature is if PWLD do not understand the health information given to them they are more likely to have poorer health outcomes (DeMarco and Nystrom, 2010; Marcus, 2006).

## **2.12. Research in learning disabilities**

Positive assumptions of objectivity prevail and can be clearly seen within the national health agenda with the National Institute for Health and Care Excellence (NICE, 2017) adopting a tier of objective evidence. Sitting at the top of this hierarchy are randomised controlled trials with qualitative subjective evidence being deemed the least epistemological. However, research that upholds a classification of diagnosis ensures that knowledge is possessed by the professional. This traditional authority is based on the rightness of accepted

customs which offer high rewards for professionals and maintain their position in society from the comfort of a scientific paradigm (Haralambos and Holborn, 2009).

The traditional role of conducting research became the subject of much debate. *Whose side are we on?* was a question interpretive sociologist Becker (1970) asked about the lives of people labelled as outsiders, such as disabled people. Some other key pieces of social research from interpretive sociologists (Wolfensburg and Tullman, 1989; Edgerton, 1967; Goffman, 1961) have shaped the thinking about disability issues. Wolfensberger's reformulation of the normalisation principles steered the agenda for learning disabled research (Chappell, 2002; Emerson, 1992). However, Yates *et al.* (2008) argue the emphasis of normalisation is on social influences that act on the individual with the person being largely hidden. This is illustrated in Atkinson's *et al.* (1978) positivist study of PWLD being discharged from long-stay institutional care. Their task, as they saw it, was to ensure the individuals had socially adequate skills to function within the community with the assumption that the individual is disabled by their impairment, rather than exploring how socially constructed barriers disable people.

Oliver (1993) also identified disabilities as being socially created within industrial societies and argued that disabled people and researchers should work together to construct a more appropriate research enterprise. Compared with traditional research, research of this nature requires a radically different relationship, with a crucial shift from doing research *on* people to doing research *with* people (Barton, 2005; Barnes, 2002).

Walmsley and Johnson (2003) view inclusive research as akin to participatory and emancipatory research. The rationale for such an approach within the area of disability has been well documented (Atkinson, *et al.*, 2000; Rodgers, 1999; Riddell *et al.*, 1998; March *et al.*, 1997; French and Swain, 1997; Whittaker, 1997; Cocks and Cockram, 1995; Rioux and Bach, 1994; Oliver, 1992; Zarb, 1992). However, emancipatory and participatory research paradigms differ



considerably, and their meanings are often contested (Ham, *et al.*, 2004; Ramcharan, *et al.*, 2004), yet both share the aspiration to include disabled people in the research process.

One of the main distinctions between the two lies in the relationship between the disabled person and the researcher (Chappell, 2000). Emancipatory research is accountable to and controlled by disabled people, whereas participatory research refers to relationships with individual participants (Zarb, 1992).

In emancipatory research the participants are not only expressing their point of view or facilitating a survey, but they also have the opportunity to gain the ownership of the whole research process. The research subjects lead all the research activities, from the decision of the research strategy to the results dissemination, with the shift in power allowing individuals to be actively part of the knowledge production and the decision-making activity. Barnes (2002) stated the definition of emancipatory research should be judged by its ability to empower disabled people through the research process, and identified key characteristics that needed to be included, such as being accountable to the disabled community, adhering to the social model of disability, and having meaningful practical outcomes for disabled people.

On the other hand, participatory research offers shared power between the researcher and the researched, with the research agenda developed through consultation, joint planning and shared responsibility (Swartz, Nyamnjoh, 2018, Cornwell and Jewkes, 1995). It is the participatory approach which has been predominately embraced by learning disability researchers. This may be because participatory research is better suited to this cohort of individuals, especially as they may require support to convey their experiences in a way that is acceptable to the research community. Kiernan (1999) pointed out that it was not until the 1980s that PWLD were involved even as interviewees in research or their views sought in evaluations of the services they received. However,

there is now a growing interest in participatory approaches to research where PWLD are involved in planning and carrying out research studies (Gilbert, 2004; Ramcharan, *et al.*, 2004; Walmsley & Johnson, 2003).

In their discussion of participatory and emancipatory approaches, Paul Ramcharan and colleagues (2004) pointed out that communication and other skills are important if PWLD are to participate meaningfully in research. This, they argued, means that people with profound or multiple learning disabilities are less likely to be included in research or have their views represented (Ramcharan, *et al.*, 2004).

Kiernan (1999) captures the political nature of qualitative research with PWLD by identifying that when seeking experiences of PWLD there are substantial barriers between the researchers and the less powerful researched. A good example of this point is highlighted in the ineffectiveness of user-friendly information for PWLD discussed in the *Let Me In- I'm a Researcher* study (Department of Health, 2006). This study notes many researchers only thought about accessible information for the participants once the project was ongoing, and where projects used accessible leaflets, the leaflets were found by PWLD to be ineffective. Cocks and Cockram (1995) similarly argued that participatory methodologies challenge researchers' monopoly on knowledge creation and advocated the use of the participatory research paradigm to involve PWLD in knowledge creation. There is evidence that policy makers are recognising that PWLD offer valuable insight into the inside story and lived experience and, therefore are, increasingly beginning involved in participatory research that is influencing the political agenda. Examples can be seen in both the Making Us Count (2005) and Count Us In (2003) research studies that examined mental health difficulties within this population. The research utilised a range of forums to give PWLD, and their family carers, a louder voice to improve the support and services available in the future. Another worthy example of research undertaken by PWLD about their experiences of undertaking research can be seen in March *et al.* paper (1997) showing how research can capture the viewpoints of PWLD (Minkes, *et al.*, 1995). It is this participatory approach,

which enables the participant to describe their lived experiences, that this study is positioned towards.

In turning to literature that explores subjective views of psychosis, various papers have been published that examine the experiences of individuals (Windell *et al.*, 2015; Ben-David, 2014; Haddock *et al.*, 2011, Knight *et al.*, 2009; Roe and Lachman, 2005; Estroff, 1989) but these do not include PWLD. Two papers have explored subjective experience of psychosis in PWLD (Robinson *et al.*, 2010; Cookson and Dickson, 2009) but neither used any augmented systems to aid communication. The CORE System Trust (Barton, 2016) have developed an accessible pictorial questionnaire to use with PWLD receiving psychological therapy. Out of the fourteen questions within the questionnaire a few highlight symptoms relating to psychosis, such as having difficulty sleeping, having feelings of loneliness, and feeling picked on, but most of the questions relate to anxiety and depressive symptoms and would therefore not be relevant to use as a self-reporting psychotic symptom tool. Within the literature there is a dearth of research that explores subjective psychotic symptoms in PWLD with or without the use of Easy Read or accessible information.

Barton's (2006) work in researching with PWLD suggests that two key questions should be asked: *who is this work for? and what right do we have to undertake it?* Tuffrey-Wijne, *et al.*, (2008) also reiterates this view. In their initial research, they started by examining how PWLD experience an illness, what helps and hinders, and how can we best support people. In undertaking the study, they realised that the position is not *if* we should be including PWLD in research, but *how*.

## **2.13. Summary**

This chapter introduced and discussed the findings of an in-depth review of literature surrounding the research topic. The literature identified was

categorised and discussed systematically in terms of the research topics covered and the bodies of existing knowledge on these topics. Existing literature was explored in terms of the methodology, findings and contribution to an understanding of PWLD in relation to social history, mental illness and self-reporting of psychotic symptoms with the aid of Easy Read information.

To understand the rich phenomenological data that comes from the lived experience of PWLD it may be necessary to support them to convey their story with communication aids, to enable them to validate their experiences. Closer evaluation of the research literature revealed a preponderance of qualitative studies on aspects of psychosis and PWLD with little evidence of subjective analysis. The literature review enabled the researcher to confirm that there is an absence of evidence on individuals with learning disability being supported to self-report their psychotic symptoms or lived experience.

Given the lack of research into how PWLD experience and self-report their psychotic symptoms, this research aims to elucidate and evidence when PWLD are given the right Easy Read resources if they can identify their own symptoms.

The underlying objectives of this research were to develop, implement and evaluate an Easy Read set of sort-cards to assist PWLD, who have suffered from psychosis, in the identification of their individual psychotic symptoms. A qualitative research methodology was used in the form of focus groups and semi-structured interviews.

Within this research the term psychosis or psychotic symptoms will be adopted to distinguish from other mental health conditions, such as depression and anxiety.

The objectives of the research were conducted in two interlinked phases, being:

**Study 1:** Developing an Easy Read psychotic symptom sort-cards tool.

1. To explore and identify with PWLD an appropriate symbol that matches a description of a symptom of psychosis.
2. To use the chosen symbol together with the symptom description to create a set of Easy Read sort-cards.

**Study 2:** Implementing and evaluating the Easy Read psychotic symptom sort-cards tool.

3. To explore if the Easy Read sort-cards can enhance the reporting of psychotic symptoms for people with mild learning disabilities.

Introductions into the philosophical, strategic and methodological framework will be detailed within the next chapter, to provide a step-by-step account of the methodology that will be employed throughout the research.

## **Chapter 3: Methodology**

### **3.1. Introduction**

The previous chapter included a detailed examination of research literature to highlight what research has been conducted, and what is already known about developing Easy Read resources to help PWLD describe their psychotic symptoms. The literature review showed there is a lack of qualitative studies that focus on the lived experience of PWLD and their self-reporting of these experiences. To gain the most detailed and rich descriptions of PWLD's narrative a thoughtful consideration of potential research designs was required. The aim of this chapter is to discuss the theoretical perspectives underpinning this research and, in turn, what guided the methodological approach that has been adopted for this study. The chapter will then go on to outline the methods and the participant criteria.

The purpose of this research is to develop, implement and evaluate an Easy Read set of sort-cards to assist PWLD to identify and gain an insight into how they make sense of their psychotic symptoms. It is argued that the most appropriate way to capture this is to gain detailed personal accounts through research that is qualitative in nature.

Qualitative research is a social inquiry that focuses on the way people decipher and make sense of their experiences and the world in which they live. Qualitative research starts with assumptions and the use of interpretive and theoretical frameworks that inform the research study in understanding the meaning individuals, or groups, ascribe to a social or human problem (Creswell, 2013). It is an umbrella term for numerous approaches spanning different discipline perspectives such as anthropology, sociology, biology, cognitive psychology, and history (Tesch, 1990).

Whether we are aware of it or not, we bring certain beliefs and philosophical assumptions to our research design (Creswell, 2013). Each of us understands the world related to our perceptions and encounters, which in turn provides the

authority of our knowledge or ontology. This individual understanding shapes the researcher's view on what constitutes acceptable knowledge and how this knowledge frames the understanding of the phenomena being studied. Qualitative researchers have underscored the importance of identifying these beliefs and theories that inform research and, as with all research endeavours, it is important to initially question the research paradigm that is best suited to acceptable knowledge.

Some authors (Neuman, 2011; Saunders, Lewis and Thornhill, 2003; Berry and Otley, 2004) advocate the importance of overtly identifying the research paradigm as it enables a justification of the theoretical assumptions and fundamental beliefs of the researcher, but, when it comes to human and health sciences, there is no agreement on the ontological assumptions with different theorists having different approaches to reality (Porter, 1998).

### **3.2. Research paradigms**

A research paradigm, a term coined by Thomas Kuhn, is a set of common beliefs and agreements shared between researchers about how difficulties should be understood and addressed or how we look at the world (Guba and Lincoln, 1989; Kuhn, 1962). Kuhn (1972) suggested that what we see depends on what we look at and what previous visual-conceptual experiences have taught us to see. For example, while a sociologist and a psychologist may observe the same reality the former may focus on the social structure and the latter may focus on interpersonal differences (Bowling, 2000).

Researchers cannot divorce themselves from the cultural, social, and political context of their work and need to be aware of value-laden assumptions and overtly identify their philosophical paradigm stance. A paradigm contains the researcher's assumptions about how they define truth and what the truth contains, how they come to know the truth, how the investigation should be undertaken, or the methodology used, and the underpinning values, or axiology

(Plack, 2005). These assumptions trickle through to the lower levels of the research study and influence the research process (Burrell and Morgan, 1979). According to Guba (1990) research paradigms create a holistic vista of how knowledge is viewed and how we can see ourselves in relation to this knowledge: leading to the methodological strategies we use to discover it. No one paradigmatic or theoretical framework is correct but as a general rule of thumb, a positivistic paradigm typically assumes a quantitative methodology, while a constructivist or interpretive paradigm typically utilises a qualitative methodology.

Several sets of assumptions underlie social research; they are often referred to as the positivist and the interpretivist paradigms (Bryman, 2008). Positivism, a term created by Auguste Comte (1974), is concerned with the positive application of knowledge and was the dominant epistemological paradigm in social science from the beginning of the twentieth century.

As positivism grew in influence it branched into two main directions; logical positivism and critical rationalism. Logical positivism, a product of the Vienna Circle in the 1920's, revolved around the idea that a hypothesis should be set and vigorously tested until it becomes statistically true. Bryman (2008,) notes that the positivist approach has gone through several stages of evolution and, although many different versions overlap, they rarely agreed precisely on its essential components.

Researchers who follow the positivist tradition seek to explain, predict and control phenomena with universal laws, believing that there is a single reality that requires the application of a natural science lens to understand social sciences. Ontologically, positivists share a common view that social reality can be measured directly through observation. Epistemologically, they advocate for the use of scientific approaches, testing theory with hypotheses and experimental statistical tests. They attempt to eradicate all contaminating factors and strive to control as many variables as possible. They suggest only observable phenomena is credible and are, therefore, more likely to utilise



quantitative methods. In essence, positivism argues that reality consists of what is available to the senses, that is what can be seen, smelt, touched, etc. and that an inquiry should be based upon this scientific observation. Hence, they advocate ideas only deserve their incorporation into knowledge if they can be put to the test, as both the natural and social worlds operate within a strict set of laws, which science has to discover through empirical inquiry.

It is impossible, however, to prove many things beyond a doubt and perhaps the most fundamental flaw of positivism is its claim to certainty. For example, evidence that nine percent of individuals with red hair are susceptible to skin cancer gives limited information about the specific characteristics of a person with red hair. To understand the person, approximations of universal laws are not as informative as a thorough analysis of the individual themselves. A widely cited example of the distortion of reality by positivist methods is within Durkheim's (1952) study on suicide. His hypothesis was that Catholic countries would have a lower suicide rate than Protestant countries, basing his assumptions on the religious affiliation acting as an indicator of social integration. Durkheim collected data on suicide rates, based on death certificates, across countries. He assumed the information was correct and could be taken as a social fact. His assumptions were flawed because for a death to be recorded as suicide the victim's motives and intentions have to be known or assumed, otherwise, a verdict of misadventure is more likely to be recorded. As Catholicism regards suicide as a religious sin death by misadventure, rather than suicide, was more likely to be recorded on the death certificates, leading to suicide rates falsely appearing to be lower in Catholic countries.

At first glance, using positivism in the social sciences may be appealing to some as it promises to provide the assurances and certainties to situations which are often incredibly complex. However, such confidence can be misplaced in relation to the social *and* natural sciences as it fails to distinguish between the lived and social worlds. An example of this can be seen with marriage; which is both a social institution as well as a lived experience. As a lived experience, it

will alter a person's perception of it. This in turn, will affect the way in which a person interacts with it and will ultimately change the institution itself (Houghton, 2011).

Whereas, the constructivism paradigm, sometimes referred to as social constructivism or interpretivism, acknowledges the social world as a meaningful place, full of active subjects not passive objects. Furthermore, it emphasises within research the meanings of events not their causes and that the research is a product of the values of researchers and cannot be independent of them (Creswell, 2017, 2013; Heshusius and Ballard, 1996; Oliver, 1992; 1997; Heron, 1981; Reason and Rowan, 1981). This paradigm is at the far extreme of positivism, believing that there is no single reality or truth, with social reality being formed from the perspectives of the people themselves. There is a recognition that the study of humans and social life is more complex than the study of physical and natural phenomena. In other words, constructions exist in the mind of individuals and the role of the inquirer is to understand, reconstruct, analyse and critique the research participant's views (Saunders, *et al.*, 2003; Schwandt, 2003; Guba and Lincoln, 1989). The task of the researcher is not to uncover new truths about reality but to unmask them from many intangible realities (Creswell, 2013; Mertens, 2009; Blurr, 2003; Potter, 2003). Reality is, therefore, mind-dependent and a personal or social construct. Do you believe, for instance, that ghosts exist? If you do, it is your personal reality, a way in which you try to make sense of the world around you. Reality is, in this sense, limited to context, space, time and individuals or groups in a given situation and cannot be generalised into one common truth. What is true or false, therefore, is culturally bound and context dependent. Underlying this paradigm is the assumption that intensions, values, attitudes and beliefs behind human behaviour can be uncovered through inquiry and interpretation (Plack, 2005).

### **3.3. Methodology**

There should be a consistent string of thought from the epistemological stance through to the methodology and methods used. This is because the

methodology of research is helpful to form a backdrop to a study and assists in the exploration of the assumptions that are made about reality and what can be known.

Constructivism was the epistemology that underpinned this research study. Constructivism takes the view that all knowledge and therefore all meaningful reality is constructed in and out of interaction between human beings and their world (Crotty, 1998). Put simply, unlike a positivist paradigm whereby meaning is discovered and objective, in a constructionist paradigm meaning is constructed and subjective (Krauss, 2005). Constructivist Immanuel Kant argued that knowledge gained about the world is subjective knowledge in the sense that it is filtered through human consciousness. As such, he recognised individuals have varied backgrounds, assumptions and experiences that contribute to the on-going construction of reality. As these human perspectives and experiences are subjective, constructivists recognise social reality may change and can have multiple perspectives. The task of the researcher is not to uncover new truths about reality but to unmask them (Blurr, 2003; Potter, 2003).

Ontologically, constructivists emphasise that there are as many intangible realities as there are people constructing them and therefore an objective truth does not exist (Creswell, 2013; Mertens, 2009). These assumptions are a direct challenge to the positivist's conjecture about the existence of a tangible external reality (Wagner and Kawulich, 2012). Epistemologically, constructivists believe that knowledge is subjective with truth lying within human experience.

This research aims to support PWLD to narrate their own lived experience and therefore, a phenomenological approach, in the form of Interpretive Phenomenological Analysis (IPA), was used as the methodology for this study. IPA is a relatively new research methodology, which was first introduced in the 1990s (Smith, 1996). IPA is described by its proponents as a study of experience with the foundations of IPA being based within philosophy and informed by three key theoretical influences; *phenomenology*, *hermeneutics* and *idiography* (Larkin and Thompson, 2012; Shinebourne, 2011; Smith, 2011;

Smith, *et al.*, 2009; Smith, 2007 Reid, *et al.*, 2005; Smith, 2004). Smith, Flowers, and Larkin (2009) neatly summarise the co-dependency of interpretation and phenomenology, as articulated in IPA, by stating that without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen.

### **3.3.1. Phenomenology**

Phenomenology is not a unitary body of thought but instead has been developed and adapted by a number of key individuals including Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) and was adapted further by Amedeo Giorgi in the 1960s and 1970s (Wertz, *et al.*, 2011; Langdrige, 2007). Although these contributors may vary in their ideas, they come together in their emphasis on focusing upon lived experiences. Phenomenology can therefore be described as a philosophical approach to studying human experience and the way in which things are perceived as they appear to consciousness (Landridge, 2007). In psychology, the word has been used more broadly to characterise any work in research, theory, or practice that emphasises the first-person experience. In psychiatry, it has been used to denote descriptive knowledge of the symptoms of mental illnesses. The value of phenomenology is that it priorities and investigates how human beings experience the world by seeking to capture a thick description of the lived experience (Cornett-DeVito and Worley, 2005), for example, how the patient experiences the illness, how the student experiences the lecture, how the doctor experiences the patient (Adams and Van Manen, 2008).

Husserl is considered to be the founder of the phenomenological approach and his endeavour has been labelled as '*transcendental phenomenology*' (Larkin *et al.*, 2011; Crotty, 1998). Husserl argued that an essential feature of consciousness was '*intentionality*'. This means that consciousness is always directed at an object in our world and therefore people are intrinsically related to objects they perceive in the lived world (Giorgi, 1997). This assertion opposes the previously accepted understanding that people and objects are independent

and can exist in isolation. The concept of intentionality helps us direct our attention towards how people perceive objects as they present themselves to consciousness (Langdridge, 2007).

Husserl famously argued that in order to describe and fully understand any given phenomena we have to go back to the things themselves (Husserl, 1970), meaning that we take our experiences for granted and do not fully focus on them and perceive them with pre-existing expectations (Smith, *et al.*, 2009). This is an important statement for this study, in the fact that it advocates an individual's symptoms of psychosis should be examined in depth, exploring the quality of those experiences in their own right. This is in contrast to the way that experiences in mental illness are traditionally understood, with them being imposed into categories of medicalised symptoms.

Husserl continued to argue that, to achieve a deeper understanding, one can take anything that they believe and '*bracket*' it, setting it aside or to suspend their preconceptions of reality, re-interpreting information in terms of the immediate experience to allow phenomena to '*speak for itself*' (Giorgi, 1997). In relating this rhetoric to this study, when a diagnostic label is the bracketed subject phenomena, the person can set aside the labelling medical model to explore individual experiences.

Heidegger, a student of Husserl, modified phenomenology by adding an interpretative (hermeneutic) element. This interpretative element, as the name suggests, goes beyond mere description of lived experience to interpreting the hidden or underlying meaning behind the descriptions. (Lavery, 2003). Unlike Husserl, whose descriptive phenomenological approach insisted on the use of bracketing to eliminate bias when describing phenomena, Heidegger rejected a '*pre-suppositionless*' phenomenology on the grounds that anyone interpreting a phenomenon cannot rid themselves of their prior experiences (Smith, *et al.*, 2009).

Heidegger emphasised that people make sense of the world through social, historical and cultural contexts, of which we cannot detach ourselves.

Heidegger's suggestions mean that for IPA, we need to be aware of the contextual perspectives that shape interpretations. Smith *et al.*, (2009) argue that through the use of phenomenology we can gain an insight into how to study and understand human experience in its own right. For this research, participants' experiences can be understood within their contextual worlds of activities and relationships. Therefore, it was important to consider how their experiences were interpreted according to their previous experiences, as well as being coloured by societal influences, and like Heidegger, be mindful that full bracketing of our prior-knowledge, experience and preconceptions may not be achievable. As the study of experience is a complex challenge, this research did not aim to capture the universal essence of the personal experience, but instead, it aimed to understand personal perceptions and individual experiences that is '*experience close*' rather than '*experience far*' (Smith, 2011).

Giorgi (2011, 2010, 2008a,2008b,1997, 1985), inspired by Husserlian ideas, applied a step-wise set of procedures when interpreting the data from conversations between the researcher and the participant, arguing that interpretation occurs through the deliberate act of describing aspects of experience in textual form. For Giorgi, the operative word in phenomenology is to '*describe*', arguing phenomenology asks, '*what is this kind of experience like?*'.

The examination of the lived experience of distress, or more specifically psychosis, can be historically traced to phenomenological studies, with some psychiatrists advocating that the understanding and classifying of mental disorders should be based on the factors that bring it about and give it form (Sass and Parnas, 2007). Within this study, PWLD will be supported in working through the meaning of their experiences in an attempt to bring to the fore their experiences and perceptions from their own perspective and by doing so challenge assumptions (Lang 2010; Lester, 1999).

### 3.3.2. Hermeneutics

As the name suggests, IPA is an interpretative approach and is therefore informed by hermeneutics, which can be described as the theory of interpretation (Langdridge, 2007). Originally hermeneutics was concerned with the interpretation of text, initially biblical, and involved an attempt to unearth what the author of the text originally meant (Smith, *et al*, 2009).

Hermeneutics links with phenomenology through a strand of the philosophy which again includes the works of Heidegger. Heidegger (1978) bridges the gap between phenomenology and hermeneutics through the concept of '*dasein*'. He argues that our engagement with the world and our understanding of the meaning of '*the things themselves*' is always accessed through interpretation and we inevitably bring our prior experiences, assumptions and preconceptions to the process of interpretation. They go on to suggest that by engaging with text helps to facilitate the showing of phenomena that might otherwise be hidden (Smith, *et al.*, 2009).

IPA lends itself to this concept, by suggesting that the researcher, in analysing text in detail, is able to discover that which lies dormant, whether the participant who provided the text or data is conscious of this or not. The researcher, therefore, is inextricably linked with making possible the appearance of the meaning while also making sense of it. In short, the phenomenon cannot be known without the interpretation.

Schleiermacher (1998) explains how a participant will use language to provide their interpretation of a particular experience, and that the analyst can take this interpretation further by understanding the participant themselves and their context. Therefore, IPA adopts a double-hermeneutic method of enquiry. In essence, analysis is a cyclical process whereby the researcher tries to make sense of the participant trying to make sense of their experience (Smith, 2011). In this study, the text will be analysed in detail, especially as PWLD may have difficulty using language to interpret their experiences and to convey their

stories. Therefore, a fundamental part of this study is the development of an augmentative and alternative communication (AAC) tool that can support the participants to describe their own interpretations about their experiences of psychotic symptoms. The researcher will then use their personal and professional experience, and understanding of previous research, to provide an interpretation of the participants' descriptions.

The hermeneutic circle is a concept which has a high level of significance to IPA and emphasises the interactive relationship between the part and the whole (Smith, 2007). That is, the meaning of any given part can only be understood in relation to the whole and the meaning of the whole can only be understood in relation to the parts (Smith, *et al*, 2009). This relationship operates on a number of levels, for example, single word versus sentence, sentence versus complete transcription. The process of interpretation in IPA is circular and requires a repeated process of engagement with the text. This is particularly pertinent concept within this study, as PWLD may use single words rather than complete sentences in their conversational interchange and, therefore, the Easy Read AAC tool will be an integral part of the relationship between the part and the whole.

### **3.3.3. Idiography**

Idiography, the study of an individual, or single event, does not make generalisation, as nomothetic research would, in, for example, diagnostic manuals. An idiographic approach suggests that everyone is unique and therefore everyone should be studied in an individual way. (Smith, Flowers, and Larkin, 2009; Eatough and Smith, 2008; Smith, Harre and Van Langenhove, 1995).

IPA is a strongly idiographic approach as it focuses on personal perspectives and the experiences of particular individuals rather than completely losing these accounts in order to make group level claims (Smith, 2004). IPA has evolved over the years. Initially, Smith and Osborn (2003) suggested that themes from



the first participant could be used to inform the subsequent analysis of the other participants; however, a firmer commitment to the idiographic approach has been articulated in more recent writings (Smith, Flowers, and Larkin, 2009) with IPA now not setting out to make generalised claims but offers an in-depth understanding of the person which may, or may not, resonate with others in the same situation (Smith, *et al.*, 2009).

For this research, the idiographic commitment will also be represented by remaining faithful to the individual through illustrating each participant's experience, which will include transcript extracts, whilst also illustrating more general themes (Smith and Eatough, 2006). In this way a picture is built up of the general as well as the particular experiences of individuals (Smith and Osborn, 2008).

### **3.4. Interpretative Phenomenological Analysis (IPA)**

IPA's prime distinction from other methodologies, such as discourse analysis, is that it focuses on the dialogue, in that it attempts to explore how individuals ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman and Osborn, 1999). So, while IPA and discourse analysis are both heavily based in linguistical approaches, their rationales are different. IPA researchers aim to talk to the participants to learn about how they make sense of their experiences, whereas discourse analysis researchers examine what participants say to learn about how they are constructing accounts of their experience.

IPA offers an inductive method of research which seeks to explore participant's personal lived experiences and gives the participant a voice. Therefore, it is suited for the exploration of complex phenomena (Shinebourne and Smith, 2009; Biggerstaff and Thompson, 2008; Fade, 2004; Murray and Harrison, 2004; Smith, 1999). IPA allows the researcher to try and understand how the participants make sense of their own experiences to gain an insider perspective. It is especially aimed at capturing, as closely as possible, the way

in which a phenomenon is experienced within the context in which the experience takes place (Giorgi and Giorgi, 2008b). As Smith and Osborn (2003) explain, IPA is about getting close to the participant's personal world through a theoretical commitment of identification of a cognitive, linguistic, affective and physical being, assuming a chain of connection between their talking, thinking and emotional state.

Most IPA studies have been conducted using semi-structured interviews which enable the participant to provide a fuller, richer account. The process is dynamic and what emerges is a co-construction build by the ebb and flow between the participant and the researcher. The interviews are taped and transcribed verbatim and then subjected to detailed qualitative analysis. During the analysis patterns, usually called '*themes*', are identified. The themes are usually drawn from detailed, line-by-line commentary on the data, called '*codes*' (Larkin and Thompson, 2012).

As IPA studies are usually drawn from a small cohort of individuals, that have certain experiences in common, it challenges the traditional linear relationship between the number of participants and the value of the research. It retains an idiographic focus, with ten participants being at the higher end of most recommended sample sizes (Smith *et al.*, 1999).

In this study the researcher will, through a semi-structured interview and an Easy Read tool, ask the participants to reflect on the past lived experience of a psychotic episode to hopefully prompt recall and reflection.

### **3.4.1. Rationale for selecting IPA**

There are a number of reasons why IPA is the chosen methodology for this study.

- As IPA is exploratory rather than explanatory, it offers the flexibility to allow for unanticipated topics or themes to emerge, something that may be evident when interviewing PWLD.

- IPA is concerned with experience, especially human experience (Smith, 2011), which this study aims to capture in relation to PWLD and psychotic experiences.
- IPA requires the researcher to collect detailed, reflective, first-person accounts from research participants to identify what matters to the participants, and then explore what these things mean to them.
- IPA as an approach to research can be used to challenge conventional discourse or ways of thinking (Cassidy, *et al.*, 2011).
- The idiographic nature of IPA, by paying close attention to individual accounts, may disclose interesting and valuable insights for practice, especially in providing a contextualised understanding of illness-as-lived that is consistent with patients' concerns and priorities (Kearney, 2001; Toombs, 200; Jensen, 1989).
- The intent to understanding the meaning of the person's experience holds a particular appeal for the discipline of nursing, whose practise engages with people through their experiences of health and illness (Smith *et al.*, 2009; Anderson, 1991; Holmes, 1990; Benner, 1985). As Pringle *et al.*, (2011) established, phenomenological research, in the form of IPA, can offer an adaptable and accessible approach for nurses, that allows for an in-depth regard that privileges the individual, by hearing and understanding their experiences. It also acknowledges that the researcher needs to bracket (or set aside) any pre-defined theories or assumptions but at the same time use them as a source of insight (Finlay, 2008).
- IPA work has enabled the voices of often under researched groups of people, such as PWLD, to be heard (Clarkson, Murphy, Coldwell, and Dawson, 2009)
- There are several examples of IPA being applied to inquiries of PWLD (Thomlinson and Hewitt, 2017; Robinson, *et al.*, 2010; Dysch, *et al.*, 2012; Mason, *et al.*, 2013; Donner, *et al.*, 2010; Pitt, *et al.*, 2009; Knight, *et al.*, 2009). In Corby *et al.*'s (2015) systematic review of phenomenological studies involving PWLD they found IPA was utilised to study a variety of issues including, ageing, motherhood and parenting, and physical and

mental health. They found the IPA approach offered a variety of benefits, with probably the most applicable being the involvement of life decisions and information that could influence the individuals care and care plans. In Thomlinson and Hewitt's (2017) study, examining mental illness in PWLD, they identified four superordinate themes being; distress, fear and isolation; damage impact on relationships; negative view of self; and being unable to get a sparkle back. In Robinson *et al.*'s (2016) study they found that the participants did not identify with specific psychiatric labels, preferring to perceive themselves as having individual and specific needs. Donner *et al.*'s (2010) IPA inquiry, of twenty-six PWLD who had been treated on a generic psychiatric ward, were able to elicit difficulties with lack of treatment, diagnostic overshadowing, perceptions of disempowerment, and a limited use of accessible information. When examining the lived experience of friendship, Mason *et al.* (2013) reported that although PWLD have a confident understanding of how friendships should be, their lived experiences revealed that they actually had a less positive experience of friendship, resulting in negative emotions such as stress, trauma, and feelings of vulnerability. These studies suggest IPA offers a systematic and practical approach suitable for exploring the lived experiences and subjective perceptions of PWLD and can present both the participant's and the researcher's views. Although IPA relies heavily on language, when Easy Read information is provided, the participant with learning disabilities can be supported to narrate their lived experiences.

- IPA connects with several core philosophical and theoretical ideas, but views them as complementary rather than competing, and picks eclectically from them. Rather than attempting to capture the essence of a phenomenon IPA humbly aims to capture particular lived experienced of a particular group of people.
- IPA urges researchers to adopt a phenomenological attitude, or bracketing. As the researcher has extensive experience of service provision for PWLD and mental ill health a non-judgemental approach to the data, while at the same time aiming to bracket past assumptions, understandings and

knowledge will allow an opportunity to acknowledge fore-understandings and assumptions in order to get to the phenomenon (Tufford and Newman, 2010).

### **3.4.2. Limitations of IPA**

In critiquing IPA questions arise about its general application of results. However, Smith and Eatough (2007) suggest IPA studies should be regarded from theoretical rather than empirical generalisability with the findings linked to the researcher's personal and professional experience and existing literature in the area.

Brocki and Weardon (2006) reviewed fifty-two articles using IPA, concluding that it was applicable and useful in a wide variety of research topics. Smith (2010) undertook a larger systematic review and compared 293 empirical IPA studies covering a wide range of physical and mental health topics but concluded only twenty-seven percent were considered of good quality.

Both Hiles (2008) and Giorgi (2010) state that the theory and practice of IPA are not based on phenomenology at all and is not good science, as methodically it is too flexible and there is a lack of rules with regard to the researcher's conscious processes. However, Smith (2010) disputes these criticisms by Giorgi arguing that IPA has a clear theoretical underpinning in phenomenology and hermeneutics, which he detailed in Smith, Flowers and Larkin (2009). Nevertheless, Smith agrees that IPA is not a prescriptive methodology in the quantitative sense, suggesting that constraints are built-in through the professional and personal skills of the researcher (Yardley, 2000).

Regardless of the criticism, IPA can offer a means to develop a better understanding of the lived experience, by focusing more on personal meaning and sense-making, what the actual experience is like for the person and what the person is making of what is happening to them.

### **3.5. Considerations of alternative approaches**

The aim of this research is to focus on lived experience, however IPA is only one phenomenological approach which aims to do this. Pringle *et al.*, (2011) argue that it is important for a research methodology to have a strong theoretical and philosophical underpinning in order to provide a solid sense of vigour and purpose. There are a number of highly regarded qualitative methodologies available to the researcher, with examples including thematic analysis, heuristic inquiry, action research, grounded theory, and discourse analysis, that can achieve this goal (Creswell, 2017).

Langdrige (2007) highlights that descriptive phenomenology, developed by Giorgi, as a way to describe phenomena, rather than interpret it, aims to capture the underlying structure of an experience. However, the researcher wanted to fully acknowledge their role in the sense-making process and thought it was not possible to fully bracket preconceptions (even though an effort was made to attempt to do this).

Grounded theory is an approach (with multiple versions) which aims to develop a theoretical account of a particular phenomenon (Smith, *et al.*, 2009). It was developed for sociological research (rather than psychological research) in order to increase the understanding of and explain different social processes (Willig, 2013). Investigating social processes appears to emphasise understanding at the group level rather than the individual level and one of the attractions of IPA within this study was the idiographic focus.

There is evidence of where grounded theory has been applied to research involving both PWLD and learning disability professionals (Carey and Griffiths, 2017; Clement and Bigby, 2013; McCray, 2003). However, grounded theory falls short in recognising how engrained the researcher can be within the data construction. Interpretation data collection occurs over time and at many levels and it is difficult to start a study without some pre-existing assumptions (Bryant and Charmaz, 2007). Also, in keeping with the recommendations of Glaser, grounded theory should be undertaken with both observations and interviews as

part of the data collection process (Hussien, *et al.*, 2014). This two-pronged approach would be difficult within this research as it only aims to seek the lived experience of the participant's psychosis retrospectively, rather than during a person's psychotic episode.

Discourse analysis is another methodology which encompasses a number of different versions, all of which share a common concern with the constructive nature of language (Burr, 2003). There is a small body of qualitative research literature that has drawn on a discourse analysis to research PWLD (Haydon-Laurelut and Nunkoosing, 2016; Jingree, *et al.*, 2006; Drinkwater, 2005) but it has been mainly used to ascertain the views of professional staff rather than individuals with learning disability themselves. When PWLD have participated in research that employs discourse analysis there have been noted difficulties. When Scior (2003) examined how women with learning disabilities positioned themselves in relation to gender and disability they noted a tendency for contradiction and inconsistencies, with data needing to be treated with caution. Furthermore, Jingree *et al.*, (2006) found the analysis of extracts involved several alternative understandings of speaker accounts because they were unsure of the particular referents being used, the meaning of utterances, or whether the question had been misunderstood by the interviewee. They also found it difficult to identify patterns across participants because some participants gave brief responses that lacked detail. They concluded that discourse analysis can be useful in inquiries with PWLD when the speaker is more articulate, but it becomes more difficult to put together a coherent analysis when participants' communication or comprehension difficulties increase.

The key theoretical perspectives of IPA are phenomenology, hermeneutics and idiography (Smith, Flowers, and Larkin, 2009; Smith, 2007; Smith, 2004). These features are not unique to IPA, but the way in which they have been combined and the specific emphases and techniques used within the method identify IPA as an affiliated but distinct approach in the field of phenomenological enquiry.

### **3.6. The epistemological position of the author**

As already discussed, selecting an appropriate paradigmatic framework is crucial because, as Guba and Lincoln (1994) suggest, it allows the researcher to create a holistic view of how knowledge is viewed and how the researcher sees themselves in relation to this knowledge, which supports the methodological strategies they will employ. After considering the paradigms the author was drawn towards constructivism as it seemed most fitting for this research.

Designing a research study begins with selecting a topic and a paradigm that reflects the framework of beliefs and values for investigating that topic. Dash (2005) provides several questions that the researcher should ask in selecting a paradigm and methodology:

1. What is the nature of the social phenomena being investigated?
2. Are social phenomena within nature or created by the human thought?
3. What are the sources of knowledge corresponding to the social reality and how can knowledge be gained and published?
4. What is the relationship of an individual with their environment?

It is the author's view that truth and meaning do not exist in some external world but are created by the individual's interactions with the world. As Schwandt (2003) states, meaning is constructed not discovered. So, individuals construct their own meaning in different ways, even in relation to the same phenomenon. Hence, multiple contradictory but equally valid accounts of the world can exist.

Although the positivist approach has its benefits, the trade-off is between rigour and relevance. As Fairhurst and Grant (2010) articulate, reality is not some objective truth waiting to be uncovered through positivist scientific inquiries. By only applying a medical model of diagnostic criteria and mental distress pathologies when looking at a PWLD's psychotic experiences, the individual is



cut off from their personal, interpersonal and sociocultural identity (Dillon and May, 2003).

Surely, psychotic symptoms should be examined from the person's experiences rather than a decontextualised approach of symptoms of a disorder and pathological biological process. Although it is recognised that a diagnosis provides useful shorthand to communicate a person's distress within multi-disciplinary working, it does not acknowledge individual experiences. An example of how valuable an individual's account of their illness can be is evident in the work of Bentall (2003), in which they offer a wealth of case stories to portray the reality of living with distress by encouraging individuals to articulate their first-hand experiences of voice hearing. Bentall (2003) argues that instead of defining an individual's mental illness with diagnostic terms such as delusions and hallucinations the person's experiences should be understood psychologically.

Schwandt (1994) questioned this constructivist's viewpoint and asked if knowledge is individually constructed how can it be extensively shared? Constructivists counter this rhetoric by acknowledging constructions are not only created by the individual but by society as well. In fact, the diagnostic criteria of learning disability is, in itself, a social construct. Society and its institutions have the power to construct disability around social expectations of health, but one cannot be learning disabled on one's own (Rapley, 2004). This is also observed within the clinical setting when an individual with a learning disability experiences psychosis. They are not routinely asked about their own lived experiences, values, attitudes, and beliefs in relation to their mental ill health experience, which in turn, leads to their illness being constructed for them within the context of a diagnostic classification and illness labelling. This can then lead to diagnostic overshadowing, with health professionals attributing physical symptoms to the person's mental illness, resulting in inadequate diagnosis and treatment. Another example of an adopted social phenomenon can be seen in the application of the term challenging behaviour. When services

are able to meet the needs of the person the behaviour is no longer challenging (Kiernan, 1999).

This research intended to explore the lived experience of people with mild learning disability who have suffered from a psychotic episode within the context of their own articulated symptoms. In exploring peoples' lived experience there can be no pre-set hypotheses. How people make meaning of subjective experiences and understand their place in the world is the concern of qualitative approaches (Elliot *et al.*, 1999) and therefore a constructivist approach is eminently suitable for this inquiry as it attempts to make sense of phenomena in terms of the meaning people bring to them (Denzin and Lincoln, 2005).

Within the goals of constructivism, this inquiry's target is to interpret and construct meaning from individual lived experiences from a traditionally marginalised group. Moreover, the author is concerned with supporting individuals to articulate subtle and unique differences of their illness, to help them access the appropriate support, at the appropriate time, and embrace a recovery approach.

From a constructivist philosophy, the social world is not a given. It is not something '*out there*' that exists independently of the thoughts and ideas of the people involved in it. It is not an external reality whose laws can be discovered by scientific research and explained by scientific theory as positivists would argue. The social world is a world of human consciousness: of thoughts and beliefs, of ideas and concepts, of language and discourse (Jackson and Sorensen, 2015). These thoughts, beliefs and concepts are often distorted by psychotic illness. Constructivism offers the opportunity to gain a '*thick description*' of individual lived experiences, going beyond the mere surface and observed diagnostic portrayal to uncover feelings and the meanings of a person's actions.

Within the constructivism domain, researchers do not strive to uncover a universal set of laws that underpin reality. Instead, they attempt to understand

the intangible constructions or perspectives that individuals form about places, events, and illnesses (Guba & Lincoln, 2004).

While it is recognised that mental health care can draw on hard sciences, such as randomised control trials, meta-analysis, and systematic reviews, the quality of core human nature cannot be fragmented into a few distinct variables for study. Each person is unique and brings with them a unique background, for example, gender, race, ethnicity, and social differences to the treatment setting. Because of this uniqueness outcomes can never be fully predicated nor controlled (Plack, 2005). Two individuals with the same diagnosis may present very differently and their illness progression cannot be pigeon-holed into neat boxes. To fully embrace person-centred care, PWLD should be supported to convey their story, with communication aids, to enable them to validate their experiences.

### **3.7. Research design**

What seems important, but what is missing from current studies and literature is an ever-growing need for interventions that empower people with learning disabilities to describe their psychotic symptoms. Services should recognise that each individual's experience is unique – no one person's illness, or way of coping with it, is exactly the same as anyone else's.

From personal clinical experience, clinicians within the learning disability field do not have access to a tool that can assist individuals with a learning disability to articulate their psychotic symptomatology. Currently, diagnosis and interventions are based on traditional behavioural observations alone, resulting in support being offered within the framework of a medical model. This is often implemented too late in the illness progression to prevent relapse. To overcome this, services need to adopt a personalised holistic approach that respects each

individual's understanding of their own events and service users should be acknowledged as experts of their own experiences.

It is apparent from the literature review that work has been undertaken to enable individuals without a learning disability to recognise and report their own unique pattern of psychotic illness progression using a set of sort-cards (Birchwood *et al.*, 2000), but this intervention has never been adapted for PWLD to use.

As already stated, this research consists of two interlinking studies, supported by some preliminary planning, illustrated in figure 7.

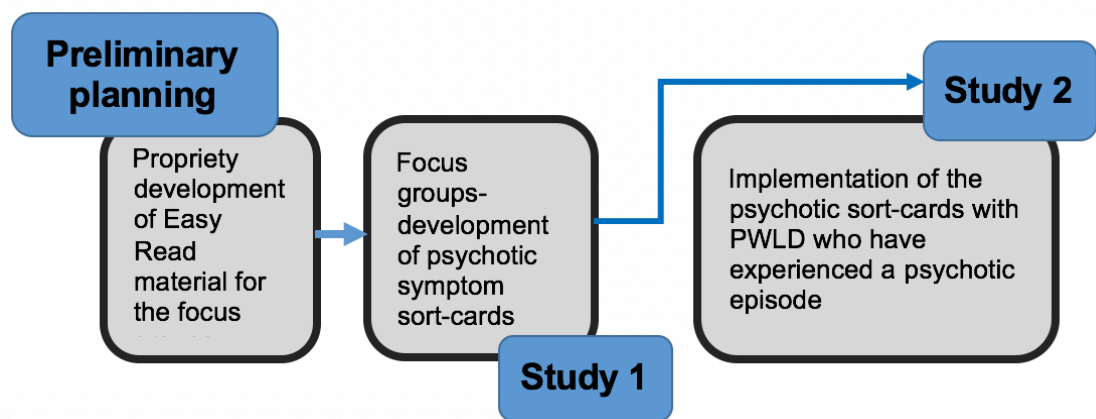


Figure 7: The study design.

In the first part of the research PWLD were asked to join focus groups to ascertain their views of both psychotic symptom statements (based on the work of Birchwood *et al.*, 2000) and the most appropriate symbol that they felt best represented the statement. The results of these focus groups were used to develop a sort-card tool. In the second part of the research the sort-card tool was utilised to explore if people with mild learning disabilities could report their individual experiences and symptoms of their psychotic illness.

### **3.8. Preliminary planning**

The first stage of the research was to utilise focus groups. To ensure that the information presented was consistent for all focus groups the author undertook some initial preparatory work to be able to present all the information in an Easy Read uniform format. As identified from the literature review, Birchwood and colleagues (2000) recognised that early warning signs, or prodromal symptoms, may signal the onset of a psychotic illness. However, attempts to predict the onset of psychosis from non-specific or dysphoric prodromal symptoms alone yielded poor sensitivities, but results were more promising when low-level psychotic symptoms were included in the predictor variable.

For these reasons, Birchwood *et al.*'s (1995) research centred around identifying and managing an individual's relapse signature, a unique pattern of early warning signs most likely to indicate impending psychotic relapse. From their research Birchwood *et al.* (1995) identified fifty-five early warning signs that they divided into thinking, feeling, and behavioural statements. These early warning sign statements were used as the underpinning drive of this research.

#### **3.8.1. Adapting psychotic statements into Easy Read**

Each of the original statements were initially analysed for the suitability of use by PWLD. Out of the fifty-five statements all but one statement was deemed appropriate. The statement 'behave like a child' was removed as it was thought that it did not fit with this population group and did not necessarily have a direct link to a psychotic symptom. To ensure each of the remaining fifty-four early warning sign statements were accessible for PWLD and written in an Easy Read format, each statement was analysed and rewritten, where necessary. Illustrated in table 1.

**Table 1: Amended psychotic symptom statements**

Birchwood sort-cards	Amended for people with LD
Behaviour cards	
Difficulty in sleeping	Difficulty sleeping
Speech is jumbled and filled with odd words	My words are strange and mixed up
Talking or smiling to oneself	I talk or smile to myself
Acting suspiciously as if under surveillance	I act like people are watching me
Behaving oddly for no reason	I do strange things for no reason
Spending time alone	I spend more time on my own
Neglecting appearance	I don't take care of how I look any more
Acting like you are someone else	I act like I am someone else
Not seeing people	I don't see people as often as I used to
Not eating	I don't eat as much
Not leaving the house	I don't go out as much
Refusing to carry out simple tasks	I don't do what people ask me to do
Drinking more	I drink more
Smoking more	I smoke more
Slow movements	I move more slowly
Unable to sit still for long	I can't sit still for long
Aggressive behaviour	I get angry a lot more

Thinking cards	
Thoughts are racing	My thoughts are racing
Senses seem sharper	My senses seem better
Thinking that one has special powers	I think I have special powers
Thinking that one can read the minds of other people	I can read other people's minds
Thinking that other people can read your mind	Other people can read my mind
Receiving personal messages from the TV	I get messages from the TV
Experiencing strange sensations	I have strange feelings in my body
Preoccupied about one or two things	There is something I cannot stop thinking about
Thinking one might be someone else	I think I might be someone else
Seeing visions or things other people cannot see	I can see things other people cannot see
Thinking people are talking about you	I think people are talking about me
Thinking people are against you	I think people are against me
Having more nightmares	I have more nightmares
Having difficulty concentrating	I cannot concentrate
Thinking bizarre things	I think very strange things
Hearing voices	I hear voices
Thinking your thoughts are controlled	I think someone controls what I think
Thinking that a part of you has changed shape	I think a part of me has changed shape
Having difficulty making decisions	I find it hard to make decisions

Feeling cards	
Feeling helpless or useless	I feel helpless
Fear of going crazy	I'm afraid I might go mad
Feeling sad or low	I feel sad
Feeling anxious or restless	I feel anxious
Feeling increasingly religious	I feel more religious
Feeling as if one is being watched	I feel like I am being watched
Feeling isolated	I feel I am on my own
Feeling tired or lacking energy	I feel tired all the time
Feeling confused or puzzled	I feel confused
Feeling forgetful or far away	I feel I am forgetting things more
Feeling strong or powerful	I feel strong and powerful
Feeling in another world	I feel far away, in a different world
Feeling unable to cope with everyday tasks	I feel like I can't cope
Feeling as if one is being punished	I feel like I am being punished
Feeling like other people cannot be trusted	I feel like I cannot trust anyone
Feeling that one does not need sleep	I feel like I do not need to sleep
Feeling guilty	I feel guilty
Feeling irritable	I feel irritable

In addition, each early warning statement was evaluated with the Flesch Reading Ease Formula. Flesch–Kincaid readability tests are readability tests designed to indicate how difficult an English reading passage is to understand, based on the core measurements of word and sentence length (Readability Formulas, 2016). The Flesch–Kincaid reading grade level was originally



developed by the U.S. Navy in 1975 (Kincaid *et al.*, 1975) and was first used by the Department of Defence for assessing the difficulty of technical manuals. Pennsylvania became the first state to use this system, insisting that car insurance policies were written at no higher than a level of fifteen-year-old reading difficulty.

There are now a number of readability tests and online readability consensus calculators that take a sample of writing and calculate the number of sentences, words, syllables and characters in the sample. The readability formulas identify the reading level of material and help to determine if the audience will be able to read the text.

The Flesch Reading Ease Formula is a test to draw conclusions of readability from shorter sentences and words. It is based on a 100-point scale with higher scores indicating material is easier to read and lower numbers mark passages that are more difficult to read, illustrated in table 2. In the United Kingdom scores for typical literature include the BBC Primary school's website with a score of 73, The Sun newspaper with a score of 60, and the Guardian and Daily Mail with a score of 58.5.

**Table 2: Flesch reading score levels.**

<b>Flesch Reading Ease Score</b>	<b>Readability Level</b>	<b>Education Level</b>
0 - 29	Very difficult	College Graduates
30 - 49	Difficult	College
50 - 59	Fairly difficult	Senior High School, A-level
60 - 69	Plain English	13 to 15-year-olds
70 - 79	Fairly easy	12-year-olds
80 - 89	Easy	11-year-olds.
90 - 100	Very easy	10-year-olds

Flesch reading score levels. [Accessed 09/06/2017] Available at: <https://readable.io/content/the-flesch-reading-ease-and-flesch-kincaid-grade-level/>)

The results of the Flesch Reading Ease test, as illustration in table 3, demonstrates that the adaptations made to the statements reduced the readability from a college graduate level to a 10-year old level in some cases.

	Sentence	Flesch Reading Ease	Flesch-Kincaid grade level
Birchwood version	Refusing to carry out simple tasks	73 (fairly easy: 12-year-old)	11.4 years
Amended Easy Read version	I don't do what people ask me to	114.12 (very easy: 10-year-old)	5.8 years

	Sentence	Flesch Reading Ease	Flesch-Kincaid grade level
Birchwood version	Acting suspiciously as if under surveillance	3.34 (very difficult: college graduate)	17.3 years
Amended Easy Read version	I act like people are watching me	103.04 (very easy: 10-year-old)	7.3 years

Table 3: Example of Flesch readability scores after amendments were made

### 3.8.2. Symbol selection

It was evident from the literature search that supporting pictures and symbols used alongside text can increase comprehension (Houts *et al.*, 2006; Delp and Jones, 1996). This is also true for PWLD as it is easier to process information through visuo-motor channels, supporting both receptive and expressive language skills (Ronski and Sevcik, 1997). The acknowledgement of symbols supporting Easy Read information to increase attention, recall and comprehension, has also been endorsed by NHS England (2015) when they launched the Accessible Information Standards.

It was therefore considered appropriate to add accompanying symbols to support each of the adapted statements. As Widgit Software is the symbol-set

of choice by the local learning disability service (who hold a valid license to use the symbols within all clinical settings) it seemed fitting to use this system. Using this symbol-set also provided consistency and familiarity with other clinical Easy Read documents that are used locally. As part of the license agreement a small amount of printed symbol documents may be given away, as long as the resource does not exceed 100 different symbols.

However, as with all symbol sets, there are no symbols within Widgit Software to denote symptoms of psychosis or any symptoms of mental ill health. This is because symbols are predominately based on concrete, linguistic terms, that refer to an object or an event, rather than abstract concepts such as a psychotic symptom.

Therefore, an examination of all the available symbols within the Widgit Software package was undertaken between the researcher and a Speech and Language Therapist, employed within the local learning disability service, who had particular clinical skills in developing augmented materials. This was to ascertain the 'best-fit' symbols that had the greatest representation of the abstract concept, for each of the statements.

As PWLD may have difficulty making choices and because there was a limited availability of best-fit symbols to draw upon, two symbols were selected for each statement.

The best-fit symbols were then paired with each adapted early warning sign statement, as illustrated in Figure 8, to provide the basis for a sort-card development which was used as the format of the focus groups, within phase one of this research.

My words are strange and mixed up	
Choice 1	Choice 2
I get messages from the TV	
Choice 1	Choice 2

Figure 8: Example of best fit Widgit symbols for each symptom statement.

For the full set of the symbol choices, categorised into thoughts, feelings, and behaviours, seen in Appendix 1, 2, and 3.

### 3.9. Details of study 1: Development of a sort-card tool

The next step, being the first part of the research, involved running focus groups to ask PWLD if they agreed with, and understood, each of the adapted psychosis statements. The focus groups were also used to ask the participants to choose one of the two corresponding symbols that they consider best represented the statement.

Focus groups provide a low cost, but rich in data, method of exploring the views of PWLD. The advantages of using focus groups include the ability to collect

data quickly, for the researcher to interact directly with the participants, and to gain a large amount of information on phenomena that may be difficult to quantify, such as emotions and feelings (Stuart and Shamdasani, 2007).

Focus groups are a widely accepted method in qualitative research and are predominately used when there is little known about a subject, or where personal experiences are desirable. When conducting research with PWLD, focus groups have been used to acquire information on a variety of subjects including feedback on service design (Kaehne and O'Connell, 2010; Gates and Waight, 2007; Hoole and Morgan, 2007).

The main purpose in using focus groups for this research was to draw upon the respondents' breadth of knowledge and first-hand experience of using Easy Read information. In line with other research examples the focus groups allowed for an informal discussion focused around how acceptable the information would be for PWLD. Although focus groups are sometimes referred to as group interviews, the facilitator does not actually ask questions of each focus group member, but rather facilitates a group discussion, encouraging participants to interact with each other- a process that has been described as the 'hallmark' of focus group research (Siverman, 2011). Focus groups are also particularly useful when the researcher needs to gauge the extent of a level of agreement or contrasting views around a particular topic (Denscombe, 2010). In addition, focus groups can be enjoyable and empower participants as they are able to comment in their own words (Webster and Mackay, 2013).

### **3.10. Study 2: Implementing a sort-card tool**

The second part of the research used the information from the focus groups to develop a set of fifty-four sort-cards, each with a statement of a psychotic symptom and a matching Widgit symbol.

Consistent with IPA, face to face interviews were used to employ the sort-cards using a semi-structured schedule. As part of the interview the participant was

encouraged to spend time reading through the sort-cards to select the thoughts, feelings and behaviours that they had experienced when they were unwell. Once they had selected the cards that best described their personal experiences they were then asked to place the sort-cards in order, from the first symptom through to the last symptom that they experienced during their psychotic episode.

### **3.11. Participants**

It was envisaged that the participants for Study 1 would be selected through convenience sampling from community groups where PWLD attend, such as day centres. Initially, participants were intended to be recruited via the Community Learning Disability Specialist Health Team who provide services into these environments, by displaying a poster inviting participants to attend a focus group. The focus group would then be held two weeks after the posters were displayed to allow for potential participants to have time to consider participating and, if required, to be able to contact the researcher, or to be able to consult an advocate. Participants would then be selected according to the following inclusion criteria:

- PWLD
- Aged over 18 years of age
- Capacity to consent
- Spoken English.

The exclusion criterion was identified as individuals without a learning disability, under the age of eighteen, difficulties with spoken English and unable to consent.

It was originally intended to run six focus groups with a maximum of five participants within each group, giving a total of thirty participants. However, when the request was made to display the poster the researcher was invited to attend pre-existing advocacy groups for PWLD within the local area. A total of five invitations were received. Although it was recognised that there would be

less jurisdiction over the sample size and inclusion criteria of the participant cohort the advantages of utilising an established group negated this. Individuals within an existing self-advocacy group are committed to being in a group and have already consented to speak up for themselves and other PWLD, having an ethos 'to sort things out' (Dawson, 2002).

Convenience sampling was harnessed for Part 2 of this research. Professional staff from the local Learning Disability Community Team were asked to identify individuals who:

- have a mild learning disability
- are aged over 18 years of age
- have capacity to consent (based on completion of the Mental Capacity Act, 2005 statutory framework for assessing an individual's decision-making capacity)
- had received a diagnosis of a psychotic illness, and were in recovery
- were well enough to talk about their illness experiences
- were not experiencing any current psychotic symptoms
- were able to recall their illness based on the time-frame of their remission

The main concern in IPA is give full appreciation to each participant's account. For this reason, samples in IPA studies are usually small, which enables a detailed and very time-consuming case-by-case analysis. (Smith, Flowers, and Larkin, 2009; Smith and Osborn, 2008). In a 2006 critical review of IPA, sample sizes ranged from 1 to 35, with most studies falling in the middle of this range (Brocki and Wearden, 2006). Since then, it seems that the mean sample size of published studies continues to follow this trend with four to ten recommended for professional doctorates (Gil-Rodriguez and Hefferon, 2012; Smith, Flowers and Larkin, 2009; Turpin *et al.*, 1997). Ten participants were invited to take part in this phase of the study, which in line with the theoretical underpinnings of IPA, were selected purposively.

### **3.12. Data collection**

For the first study, each psychotic symptom statement, together with the two best-fit Widgit symbols, was displayed on a single sheet of flip chart page. In addition, each participant was given a corresponding sheet of A4 paper. The focus group participants were shown one page at a time and asked if they agreed with the wording of the statement and then they were asked to vote on which, or neither, Widgit symbol they felt best represented the statement.

IPA requires a rich and detailed account of participant experiences and researchers try to understand what an experience (object or an event) is like from the participant's perspective. Semi-structured, in-depth, one-on-one interviews with a dynamic process allows for a co-construction, built by the ebb and flow between the participant and the researcher. Semi-structured interviews allow the researcher and the participant to engage in a dialogue in real time. They also give enough space and flexibility for original and unexpected issues to arise, which the researcher may investigate in more detail with further questions (Eatough and Smith, 2008; Larkin, Watts, and Clifton, 2006; Smith, Flowers, and Larkin, 2009).

Therefore, in the second study participants were interviewed using a semi-structure format that utilised the sort-card tool. In addition, all interviews were audio taped and each participant's identified psychotic symptoms were photographed after the sort-cards had been placed in ranking order. All audio tape recordings were transcribed into hard copies. All participants were given a choice as to the location of the interview. Most participants chose to be interviewed at home, with three electing to attend a local hospital clinic.

### **3.12. Ethical considerations**

The emergence of research ethics came about after the end of the Second World War when details of horrific medical experiments came to light during the Nuremberg trials. The Nuremberg Code (1947) was published two years later



defining a set of research ethics principles for human experiment (Beauchamp and Childless, 2001).

Ethical considerations are paramount in all research, as ethics is concerned with rules of conduct and principles relating to moral behaviour. No matter what paradigm a researcher uses, ethics should be an integral part but the difference in paradigms will suggest different ethical issues. While the ethical principles of informed consent and minimising harm apply to all research, how this is interpreted within the research framework influences how ethics is regarded in a study (Fossey *et al.*, 2002).

Deontological (duty-based) approaches to ethics follow a set of principles that are concerned with what people do, not with the consequences of their actions. As phenomenology is about welcoming others and taking a step back, so the participant feels able to reveal their lived experiences, (Mortari, 2008) the researcher needs to be aware of the ethical issues that surround this complexity. Especially, as they are researching private lives and placing personal accounts in the public arena. When the researcher has another role, such as a nurse, they should also be mindful that they could be drawn into a role of duality, of practitioner-researcher, and away from that of a pure researcher during an in-depth interview (Allmark *et al.*, 2009).

Researchers should endeavour to ensure that research participants are protected from undue intrusion, distress, indignity, physical discomfort, personal embarrassment, or psychological or other harm. With research involving individuals with a learning disability, the researcher should be aware of a number of additional difficulties. PWLD may have comprehension and memory problems finding it difficult to verbalise their experiences. They may also have a tendency to respond positively or with acquiescence (Angrosino, 2004). Issues such as the status of the interviewer or the framing of the interview questions may also affect the data. Sometimes people with learning disabilities, social networks are often reliant on professionals rather than friends. The researcher needs to be particularly sensitive to this; researchers going into people's homes

could be perceived as being intrusive but are actually more likely to be misconstrued as being a friend (Stalker, 1998).

### **3.13.1. Ethical approval for the studies**

In the UK, it is necessary to make an application to the Integrated Research Application System (IRAS) for ethical review before starting research if the research involves National Health Service (NHS) patients. The primary function of the Research Ethics Committee, when considering a proposed study, is to protect the rights, safety, dignity and well-being of all actual or potential participants. In addition to ethical review, an application must also be made for research management and governance approval (this is usually referred to as R&D approval) to each NHS organisation in which the research will be carried out.

Ethical approval for this research was granted by De Montfort University Faculty of Health and Life Sciences Research Ethics Committee (Ref 1607) on 13<sup>th</sup> May 2016 (See Appendix 4 for approval letter).

Approval was also granted for this research by the NHS Research Ethics Committee on 21<sup>st</sup> October 2016 (IRAS project ID: 138988, REC reference: 16/EM/0235. (See Appendix 5 for a copy of HRA approval confirmation letter).

### **3.13.2. Informed consent**

Another duty-based principle is that of informed consent, including the provision of all relevant information about the research and what taking part will involve, including risks. Ensuring informed consent from the participants is not only a legal requirement but a moral obligation. Good practice regarding consent to participate in research applies to PWLD in the same way as it applies to any other human subjects (Wiles *et al.*, 2008). Scott *et al.* (2006) outlined the three key issues for PWLD when seeking consent from them. Include the person's competence to give consent, the extent to which the research is in the person's

own best interest, and the balance with public interest. The participant must be able to understand the information and agree to take part voluntarily, free of coercion or influence. Generally, consent will be obtained by asking the research participant to confirm their consent by signing a consent form, by giving recorded verbal consent or by returning a questionnaire (Israel and Hay, 2006). This process should be made accessible to ensure the PWLD understand all the information offered to them. For both parts of the research, informed consent was sought and obtained from each participant, in an Easy Read format, which explained that they could withdraw from the research at any time without giving a reason. If consent was given, the participant was asked to sign a written consent form before commencing the data collection. In addition, repeated explanations, allowances for processing time, and observations for participant distress was undertaken throughout the research.

### **3.13.3. Privacy and Confidentially**

For both studies, Easy Read participant information sheets, with additional carer information sheets, were developed and given to the participants before the commencement of the research. All consent forms, together with any other data collection information was stored securely in a locked cabinet within a NHS building and all electronic data was stored anonymously on a NHS secure network. All data will be stored for seven years after completion of the study and then destroyed.

Researchers should endeavour to ensure that all data is treated with appropriate confidentiality and anonymity. Anonymity goes further than confidentiality, as the researcher does not collect named data at all. This means the researcher cannot identify which respondent gave the data (Punch, 1994). All participants were informed that the data from both parts of the research would only be used for the sole purpose of this particular research project. Data from Study 1 was collected anonymously with only the group location been

recorded. For the second study, all participants were given a pseudonym name, so real names could not be used to identify any of the participants.

#### **3.13.4. Participant wellbeing**

It is recognised that within part two of the study the interview process involved a discussion of personal experiences and, as such, could be distressing for the participants. Although the researcher is experienced in working with PWLD who have experienced mental illness it was recognised that they were interviewing the participant within the role of a researcher and not as a clinician. Therefore, an additional clause was added to the consent form to authorise the researcher to discuss any distress with the individual's relevant health worker, ensuring that they would receive timely and appropriate support. Throughout the interviews the participants were observed for any signs of distress.

Participants were invited to choose the location of both the focus groups, and interviews, in which they would feel most comfortable. They were informed that they could have someone present throughout the interview if they wished. Prior to and before the interview participants were offered detailed information on the purpose and content of the interview.

#### **3.14. Data analysis**

Within the first part of the study data was analysed by the number of votes each symbol received, with the symbol receiving the most votes being adopted into the sort-card tool.

For the second part of the study data analysis was carried out within the IPA framework, following the steps suggested by Smith, Flowers and Larkin (2009) in their guide to carrying out IPA studies. It is recommended that the researchers totally immerse themselves in the data or in other words, tries to step into the participant's shoes as far as possible. IPA aims to evidence the participants' sense-making of the phenomena under investigation, and at the same time documents the researcher's sense making. The researcher is thus

moving between the emic and etic perspectives. The latter is achieved by looking at the data through psychological lens and interpreting it with the application of psychological concepts and theories which help illuminate the understanding of research problems.

Smith *et al.*, (2009) outline a number of stages involved in data analysis which can be used flexibly, and adapted by individual researchers, to help guide the process. The developing analysis involved moving from a focus on the individual to a more shared understanding and from a descriptive level to a more interpretative one (Smith *et al.*, 2009)

The steps are outlined below. However, it should be noted that the analysis within this study was more a cyclical process than a linear one, with the hermeneutic circle considered in order to understand part-whole relationships. Further descriptions of the analysis and how it applied to this study can be found in Chapter 5.

- **Step 1: Reading and rereading:** Each transcript was read whilst listening to the interview recording. The transcript was then read twice more.
- **Step 2: Exploratory commenting:** The transcript was read again, and descriptive notes were made on the left-hand margin of the transcript that focused on the participants description of their psychotic symptoms.
- **Step 3: Developing emergent themes:** The initial notes were read through and a higher level of interpretation was applied to capture the essence of the experience that was being communicated in the transcript.
- **Step 4: Searching for connections across emergent themes.** This stage involved mapping how the emergent themes fitted together.
- **Step 5: Moving to the next case.** The same process was repeated with each transcript.
- **Step 6: Looking for patterns across cases.** In this stage, the themes were re-examined to gain an overall picture and to identify any super-ordinate, or higher order themes, and sub-ordinate themes.

### **3.15. Conclusion**

This chapter has discussed paradigms of research and the methodology approaches that fall under these paradigms. In examining these concepts, and in relation to both the purpose and practicalities of this research study IPA offered the best fit. From an ontological perspective, IPA focuses on subjective reality from the viewpoint of the participant. This research study aimed to explore the lived experience of a PWLD and a psychotic episode. Furthermore, for IPA, knowledge arises from the meaning the participant makes of their experience, or reality. This methodology encourages the acquisition of knowledge through meaning making, by the participant and by the researcher. This chapter also detailed the methods used and the ethical considerations of research for PWLD. The upcoming two chapters will discuss in detail the methods and results of the two studies in sequence.

## **Chapter 4: Study 1- Development of a sort-card tool**

### **4.1. Introduction**

The concept of focus groups is perhaps most easily described as a group of people with a shared interest, for example, life experience and expertise, that are brought together to discuss a particular issue (Bloor *et al.*, 2001). This chapter describes the method of conducting the first part of the study using focus groups. It will discuss the participant's characteristics, data collection and data analysis, and finally will summarise the results obtained. The aim of Study 1 was to develop a sort-card tool that described symptoms of psychosis that is accessible for PWLD. The purpose of conducting focus groups was to ascertain the opinions and experiences of PWLD on the appropriateness of the Easy Read information.

### **4.2. Method**

#### **4.2.1. Recruitment of participants**

It was envisaged that recruitment to the first part of the study would be difficult as most adults with learning disabilities are outside the remit of specialist health services. Therefore, the initial intention was to select participants through convenience sampling from community groups where PWLD attend, such as day services. This was because there was an assumption that these groups would have a homogeneous population, with similar characteristics, share the same background of experiences, and could generate their ideas within a familiar social context. It was predicted that team members from the Community Learning Disability Specialist Health Team, who provide services into these venues where PWLD attend, would display a poster inviting participants to participate in a focus group (Appendix 6). The focus group would then be held

two weeks after the posters were displayed to allow for potential participants to have time to consider participating and, if required, to be able to contact the researcher or to be able to consult an advocate if they required more information. It was originally intended to run six focus groups with a maximum of five participants within each group, giving a total of thirty participants for the research.

However, when the request was made to display the poster the researcher was invited to attend pre-existing advocacy groups for PWLD within the local area. A total of five invitations were received. Although it was recognised that focus groups are often made up of small, deliberately chosen groups with a defined inclusion criterion, it seemed more appropriate to use these established networks of PWLD. Especially as they had volunteered their services, and had experience of advocating the needs of PWLD. In addition, by using these existing groups it ensured that those consulted were supported by others who are skilled in running self-advocacy groups and empowering individuals with a learning disability to be fully supported to give their views in a safe and inclusive environment. In using these already formed groups a level of confidence could be assumed in that the feedback obtained would be clear, well-informed and reliable.

Each self-advocacy group was given copies of an accessible information sheet for the participant and an information sheet for the participant to give to their carer/support worker, if they chose to. The information sheets for the carer/support worker enabled the individual's support network to have an insight into the study's intention and could, therefore, support the participant in deciding whether they wished to take part or not. The information sheets were given out two weeks prior to the arranged focus group. The information sheets offered details about the research, how the data would be treated, information on taking part and withdrawing, and details of where they could get further information (Appendix 7 and 8).



### **4.2.2. Participants**

The numbers in each of the focus groups varied. The largest group had thirteen members, two groups had eight members, one had five members, whereas the smallest group had four members. Giving a total of thirty-eight participants, across all five focus groups.

The participants were of mixed gender, age, and had a range of cognitive and physical disabilities. It is worthy of note that there were some key differences between the groups, with some groups having a higher proportion of participants with more complex needs, such as sensory impairments or physical disabilities. Whereas, other groups consisted of participants with more experience of advocacy, with some members having other prominent roles such as supporting chairs to local Partnership Board meetings. These differences were seen as strengths as it demonstrated that a greater cross-section of views was sought.

### **4.2.3. Focus group procedures**

All focus groups followed a very similar format to ensure that the information presented was consistent between groups. Prior to each focus group session, each of the fifty-four psychotic symptom statements was written onto individual flip chart pages. The corresponding best-fit Widgit symbols for each statement were enlarged onto A4 sheets of paper and attached to the related flip chart page, under the psychotic symptom statement. The two corresponding Widgit symbols for each statement were also numbered choice one and choice two.

The focus groups were facilitated by both the researcher and an additional facilitator, a qualified learning disability nurse from the local Learning Disability Specialist Health Service. The presence of the supplementary facilitator allowed the participants to be supported, both prior and during the group session, with additional information that they may have needed. The researcher was conscious that some of the terminology may not have been easy to understand,

so time was spent to ensure that those present understood the words and ideas under discussion. All the focus groups were also attended by staff members who usually support the advocacy group meetings.

Before the groups began the participants were welcomed and there was a general introduction. Each participant was once again given a copy of the information sheet. This was used to reiterate the remit of the group and the research aims. The participants were then given a copy of the consent form. Each sentence on the consent form was read out and each section was explained (Appendix 9). Each participant was asked to tick the individual sentences, if they agreed with them and then to sign the bottom of the consent form before the data collection began.

As mental illness is an abstract concept and many of the participants did not have a lived experience of mental illness, they were offered a verbal explanation of the illness terms. The participants were also provided with a visual handout that offered an Easy Read description of psychosis (Hampshire Partnership NHS Trust, 2008) (Appendix 10).

The group was introduced to each psychotic statement and best-fit Widgit symbols, displayed on the flip chart. Each participant was also given an A4 sheet of paper containing the same corresponding information as on each of the flip chart pages, illustrated in figure 9.

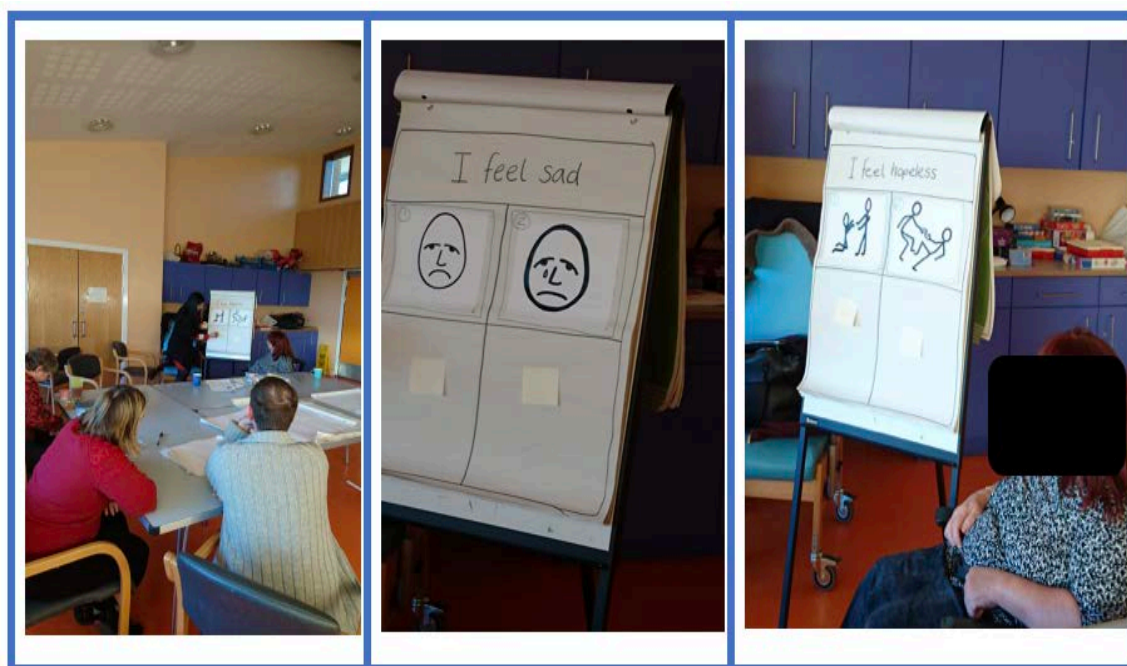


Figure 9: Focus groups with a psychotic symptom statement together with two Widgit symbols

To enable the participants to interact with each other, and with the presenting information, they were all given a pad of post-it notes. Each psychotic symptom statement was read out and the group were asked if they agreed with the wording. Then the participants were asked which of the two Widgit symbols they thought best represented the statement, choice one, or choice two, or neither. They were then asked to vote by individually coming up to the flip chart and placing a post-it note under the symbol of their choice. For some individuals who used a wheelchair, access to the flip chart stand was difficult, so they were asked if they would prefer for either the flip chart stand to be moved towards them or if they wanted to be seated close to the stand.

Throughout the sessions, it was recognised that some people required more support than their peers, for example a longer processing time. Therefore, statements were re-read where necessary, additional time was allowed for them to vote on the Widgit symbol, and they were supported to have equal participation within the group.

The exercise was repeated until all fifty-four statements and corresponding symbols had been reviewed by the group. The groups were then asked if they were happy with their decisions and if they needed to review any of their choices.























### **4.3. Data analysis and findings**











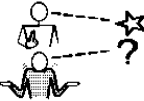
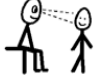




All the focus groups agreed that the wording of the psychotic symptom statements was suitable, and no changes were made.

The number of votes that were received for each symbol, for all five focus groups, were added together to give an overall score for each symbol. The results of the votes relating to each psychotic symptom (categorised into thoughts, feelings, and behaviours) and corresponding Widgit symbols are shown in tables 4, 5, and 6 overleaf.

**Table 4: Results of the chosen Widgit symbol for each of the psychotic symptom statements for thoughts.**

### Thoughts

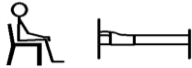



















No.	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
1	My thoughts are racing		16		11
2	My senses seem better		21		6
3	I think I have special powers		19		10
4	I can read other people's minds		13		16
5	Other people can read my mind		16		11
6	I get messages from the TV		11		18
7	I find it hard to make decisions		15		11
8	I have more nightmares		13		16
9	I cannot concentrate		13		19
10	I think very strange things		18		10
11	I think something controls what I think		9		19








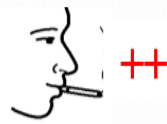


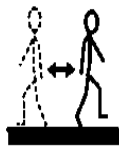



No.	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
12	I hear voices		20		9
13	I think a part of me has changed shape		18		11
14	There is something I cannot stop thinking about		18		19
15	I have strange feelings in my body		16		11
16	I think I might be someone else		6		15
17	I think I can see things other people cannot see		11		13
18	I think people are talking about me		20		7
19	I think people are against me		16		11



**Table 5: Results of the chosen Widgit symbol for each of the psychotic symptom statements for behaviours.**

**Behaviours**




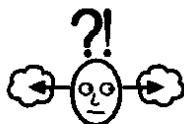






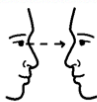
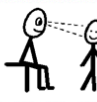

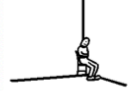




No.	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
20	Difficulty sleeping		12		15
21	My words are strange and mixed up		17		12
22	I talk or smile to myself		11		15
23	I act like people are watching me		14		13
24	I do strange things for no reason		13		17
25	I spend time on my own		17		13
26	I don't take care of how I look any more		15		14
27	I act like I am someone else		16		13
28	I don't see people as often as I used to		11		17
29	I don't eat as much		18		9















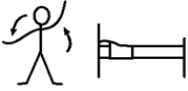
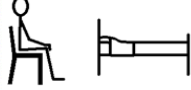


No.	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
30	I don't go out as much		20		8
31	I don't do what people ask me to		16		11
32	I drink more		13		17
33	I smoke more		16		12
34	I move more slowly		21		8
35	I can't sit still for long		14		15
36	I get angry a lot more		12		17



**Table 6: Results of the chosen Widgit symbol for each of the psychotic symptom statements for feelings.**

**Feelings**

	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
37	I feel hopeless		18		9
38	I'm afraid I might go mad		13		16
39	I feel sad		14		14
40	I feel anxious		12		17
41	I feel more religious		12		17
42	I feel like I am being watched		15		12
43	I feel I am on my own		14		17
44	I feel tired all the time		9		19
45	I feel confused		17		9

No.	Psychotic symptom statement	Symbol choice 1	Total votes received	Symbol choice 2	Total votes received
46	I feel far away, in a different world		23		7
47	I feel I am forgetting things		21		8
48	I feel strong and powerful		23		7
49	I feel I can't cope		19		9
50	I feel I am being punished		12		18
51	I feel like I cannot trust anyone		16		13
52	I feel irritable		18		9
53	I feel like I do not need to sleep		16		12
54	I feel guilty		21		7

Some participants chose not to vote for every symbol and one group did not complete all of the fifty-four statements. This resulted in some psychotic symptom statements and corresponding symbols receiving fewer overall votes

than others. However, the voting within the focus groups was not to obtain a statistical comparison. Each statement and corresponding Widgit symbols were seen in isolation of each other. The votes received were used to identify the preferred symbol for each individual statement only, therefore this did not affect the data collected. Each statement and symbol-set received enough votes to be able to select a preferable choice without running additional focus groups.

When reviewing the results, it became apparent that the participants had selected symbols that were linguistically and conceptually closest to the psychotic symptom statement, simple in design and without extraneous information. For example, for statement number twelve, '*I hear voices*', the focus groups chose the symbol that represented hearing, with a picture of an ear, rather than the more abstract picture of a speech bubble within the brain. For statement number 2, '*My senses seem better*', the participants once again selected the symbol that offered the best conceptual match to the statement by choosing an illustration of the five senses rather than a picture of the whole person. This would be in keeping with the understanding that PWLD require symbols with single, simple and defined meanings to reduce cognitive load and help with processing. It also showed that the focus group participants had a conceptual understanding, grasping the abstract meaning and transferring into the best-fit concrete symbol.

When the psychotic statement referred to an action the participants had a tendency to choose the symbol that had a clearer representation of that task, such as statement number twenty-nine, '*I don't eat as much*' and statement number thirty-six, '*I don't go out as much*'. The symbols that illustrated a plate of food and a person leaving a room through a door received twice as many votes compared to the other more abstract symbol. This may have been because the chosen symbols had a more concrete representation of the activity within the statement, supporting situational and functional understanding.

For other statements that had a less concrete meaning, such as statement number nine, '*I cannot concentrate*', the participants once again tended to choose the Widgit symbol that represented an action or activity rather than an abstract concept. An example is where the participants chose the symbol illustrating someone putting their head in their hands for statement number forty-nine, '*I feel I can't cope*'. The more abstract the two symbols were, the more evenly distributed the results became, as seen in statement number fourteen, '*There is something I cannot stop thinking about*', with one symbol receiving eighteen votes and the other receiving nineteen votes. This may have been because the focus group members had difficulty in seeing a relationship between functional, verbal and situational understanding that in turn would determine the level of real-world understanding. The more abstract the concept becomes, the harder it is to have an accurate interpretation of the intended meaning, supporting the participant's choice of not having a strong preference for either symbol.

For statement number forty-five, '*I feel confused*', and fifty-two, '*I feel irritable*', the participants showed a clearer affinity to the symbol that had additional supporting information: an exclamation mark. A punctuation mark can give additional emphasis to an intended meaning, in this case, an emotion. It is understandable why the participants selected this symbol against the same symbol without a punctuation mark, as it is easier to understand the projected meaning.

Due to the limited number of existing Widgit symbols to draw upon, two of the statements, being statement number twenty-five, '*I spent time on my own*', and statement number forty-three, '*I feel on my own*', used the same symbol-set. Although the participants went through another seventeen statements and symbol-sets between these two statements, they chose the same symbol for both. This shows that they were not influenced by previous choices and that they viewed each statement and the corresponding Widgit symbols as individual entities. In choosing the same symbol for two different statements

strengthened the participant's original decision and validated that their choices were based on rational decision making. To further support this view, it was apparent that the participants did not show any order bias. The results were evenly distributed across both choice one and choice two, with the participants consistently ranking their votes for a symbol based on the statement, regardless of position in which the symbol was presented to them.

Out of the fifty-four symbols-sets, fifty-three had one symbol that was preferred over the other symbol. Statement number thirty-nine, '*I feel sad*', received an even number of votes. Therefore, as both symbols were so similar to each other, the symbol with the clearest line drawing was chosen. The symbols that received the highest votes were then paired with the psychotic symptom statement. The categories of behaviour, feelings and thoughts were also colour coded blue, pink, and green respectively. Each psychotic symptom and corresponding Widgit symbol were made into a card and laminated. Illustrated in figure 10.

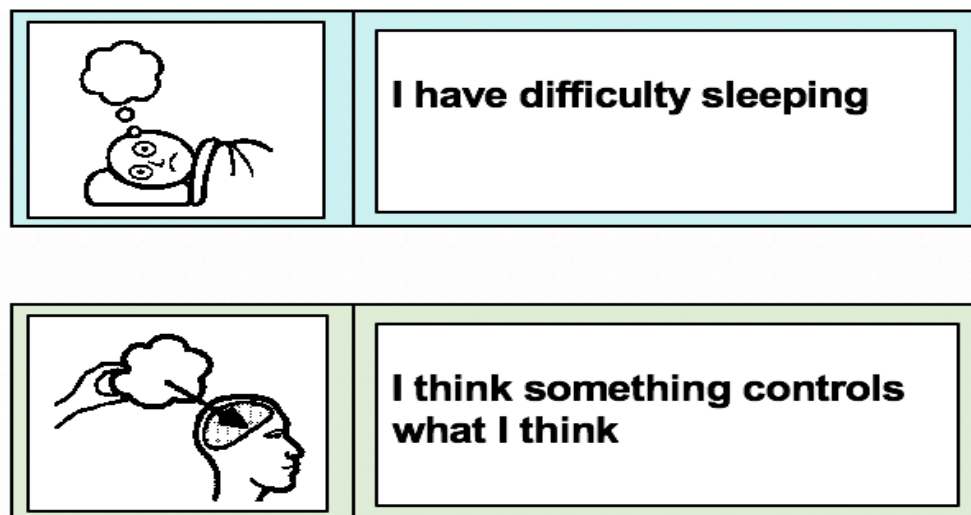


Figure 10: Example of cards within sort-card tool.

Within the focus groups, some individuals were more independent than others and were able to understand the concept of each statement quicker than some

of their peers. In these instances, the more proficient members of the groups offered their support and guidance to their counterparts. All of the focus groups were animated with the participants showing genuine passion and enthusiasm. All participants reported that they enjoyed giving their feedback and offered their services again to undertake a similar exercise, if required.

On reflection, the additional A4 copies of the statements and Widgit symbols, given out to each participant to support the flip chart information, was not used. This may have been for a number of reasons. As the participants chose to sit in a round circle formation and did not always have access to a table in front of them, they may not have had anywhere to place the additional paper. Or it may have been because the two pieces of information were too difficult to process together. It could have also been that the participants were able to interact with the flip chart and the content of the activity and therefore did not require the additional supportive information.

It was initially felt that an hour would be an adequate length of time to run each focus group, especially as PWLD has difficulty with engagement for long periods of time. In retrospect, this time allocation was insufficient, and a more realistic timeframe of two hours was required. The participants were given a choice of either ending the session completely after an hour or to rearrange another focus group on a different day. The participants, however, decided a third option and chose to continue the session until completion.

This enthusiasm was maintained after the end of the focus groups, with two groups wanting to offer further input, by suggesting amendments to or alternative symbols for the existing Widgit symbol. The largest group, of thirteen participants, asked if the researcher could organise an additional meeting so the participants could make further suggestions on alternative symbols or adaptations to the existing symbols. Therefore, another meeting was arranged to facilitate this request.

The suggested amendments and alterations were drawn by the participants on flip chart paper. For statement number one, '*My thoughts are racing*' the participants felt that this abstract concept could be better supported by adding a thought bubble that contained either a racing car or a formula one racing car. As illustrated in figure 11.



Figure 11: Amendments to Widgit symbols

For statement number five, '*Other people can read my mind*'. The participants suggested that an open book could be added to the existing symbol. Also, illustrated in figure 11.

The participants thought statement number eleven, '*I think someone controls what I think*', could be further enhanced with an addition of either a television remote controller or a console game controller to emphasise the '*control*' part of the statement. Illustrated in figure 12.



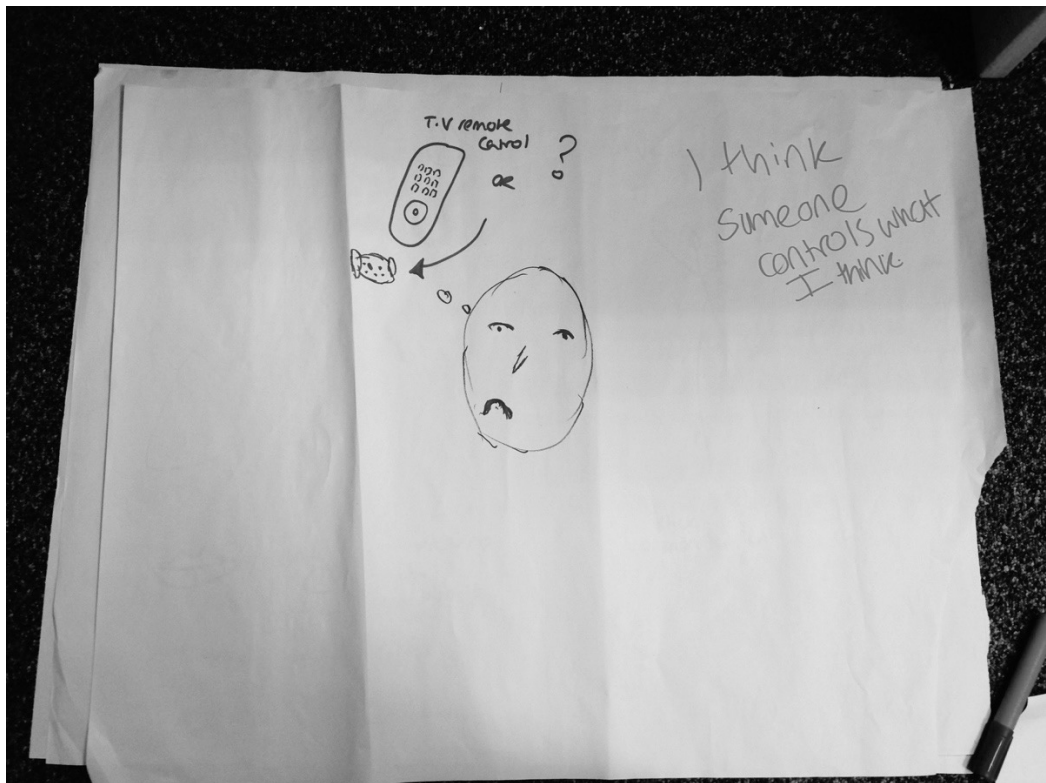


Figure 12: Amendments to Widgit symbols

The participants arrived at a general consensus that statement number thirteen, *'I think a part of me has changed shape'*, should be replaced by a symbol that contains a variety of different shaped figures, with an arrow that connected them all, supported by a thought bubble. Illustrated in figure 13. For statement number sixteen, *'I think I might be someone else'*, to groups suggested that this symbol should be supplemented by an additional illustration of a well-known super hero's face, to depict that the person may think they are someone else that is not actually real. Illustrated in figure 13.



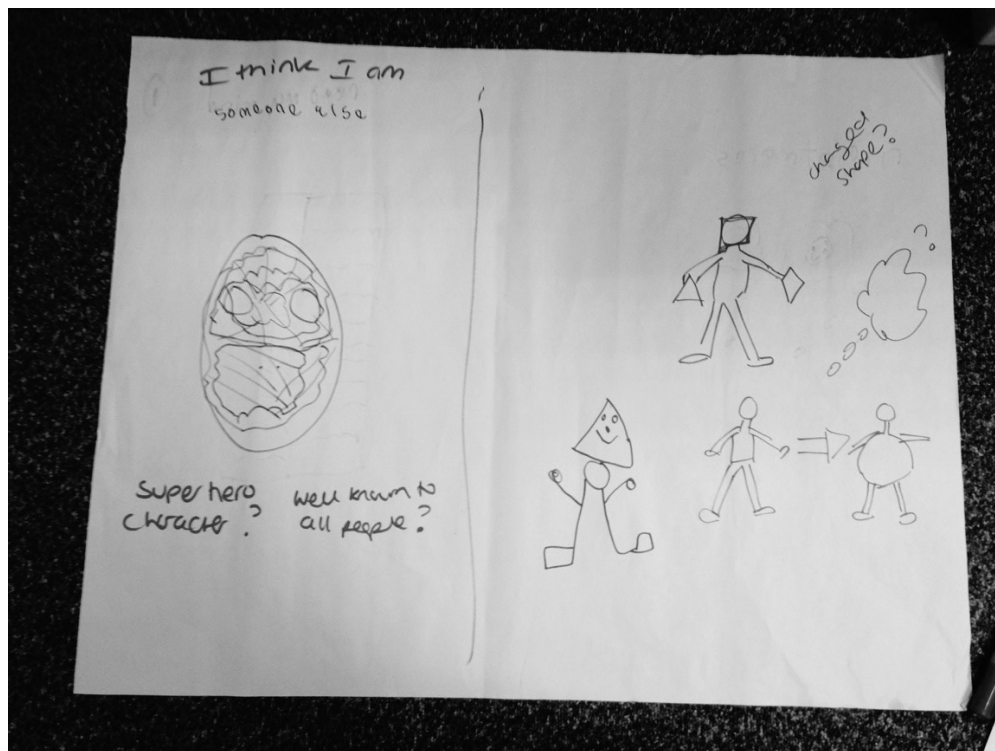


Figure 13: Amendments to Widgit symbols

Whereas, in statement twenty-two: '*I talk and smile to myself*', the participants suggested that additional thought bubbles should be added to complement the existing speech bubbles already within the symbol. Illustrated in figure 14, overleaf. The participants felt that the stick man in statement number thirty-four, '*I move more slowly*', should have the legs drawn in a variety of different positions to demonstrate movement. Illustrated in figure 14, overleaf.

They also suggested that statement number forty-six, '*I feel far away, in a different word*', should have a picture of the planet earth added. Finally, the participants advocated that statement number eight, '*I have more nightmares*', supporting symbol had a fairly good representation of the statement, but felt it could be enhanced by adding additional thought bubbles of dreams to emphasise the '*more*' within the statement.



Figure 14: Amendments to Widgit symbols

Although these suggestions were not used in this research, as Widgit symbols are copyright protected, discussions with Widgit regarding symbol development was undertaken after the research.

#### 4.4. Conclusion

The focus of this first part of the study was to develop a sort-card tool to be used with PWLD, who have experienced a mental illness, to help them to report their experience of psychotic symptoms. This was achieved by running a series of focus groups, with a total of thirty-eight PWLD. The focus groups asked the participants to comment on the wording of fifty-four psychotic symptom statements and then to choose from two Widgit symbols that they thought best supported the statement. For all fifty-four statements, the participants agreed with the wording of the statements and were able to identify one Widgit symbol

that they thought would assist in the understanding of the psychotic symptom statement. The participants showed a clearer preference for some symbols, especially when the statement had a concrete meaning. Whereas, other symbols received a more even distribution of responses. In addition, some participants were able to offer suggestions on how the Widgit symbols could be enhanced to improve the link to the context of the psychotic statements. The results were used to develop a sort-card tool which comprises of fifty-four psychotic symptom statements supported by one Widgit symbol. The psychotic statements were colour-coded into thought, feelings and behaviour cards. This sort-card tool was utilised within the second half of this study.

## **Chapter 5: Study 2: Implementing an Easy Read sort-card tool**

### **5.1. Introduction**

The second part of the study aimed to explore if an Easy Read sort-card tool could enhance the reporting of PWLD's own psychotic symptoms. This chapter describes the chosen method of the research, namely Interpretative Phenomenological Analysis (IPA), and how it was implemented. It also outlines the participant's characteristics, recruitment to the study, method, data collection, the research process, the data analysis and the results.

### **5.2. Method**

IPA was identified as the most appropriate approach for this research as it aimed to gain a detailed picture of the phenomenology of the person's experience. It is an approach that explores the perspectives and experiences of the individual by focusing on personal meaning and sense-making, rather than generating theory (Smith *et al.*, 2009).

The approach adopted by the IPA researcher is to collect data from very loose structured interviews, where the interviewer has developed a prompt sheet with a few main themes for discussion (Smith *et al.*, 1999). The prompt sheet within Study 2 used four questions and an Easy Read sort-card tool. To ensure the experiences of the participant could be explored, the interviewer only used the prompt sheet as a guide rather than it being prescriptive. After each interview, the recordings were transcribed verbatim, often including pauses, mistakes, and colloquial phrases. The transcripts were initially analysed in conjunction with the original recordings and themes were identified.

IPA analysis involves close reading and re-reading of the text (Smith *et al.*, 1999). While reading the researcher makes notes, in the margin, of any observations and reflections that they identify. This could include reoccurring phrases, emotions and language used. It should be noted that while reading the text the researcher should attempt to suspend all judgements, so they can focus on the transcript content. This involves 'bracketing' or suspending any of the researcher's assumptions and experiences.

The researcher then moves to re-read the text to identify themes, and connections between themes, that capture the person's lived experience. The next stage is to categorise the topics into super-ordinate themes that have a hierarchical relationship between them. One way of obtaining this is to record the themes using a summary table in order for the main features, which have been identified by the participants, to be captured. This is supported by evidence from the interview, using quotations, to capture the essence of the participant's thoughts, feelings, and emotions. As an alternative, the researcher can use a master list of themes from the first text and add to these, and any other new themes, from the subsequent interviews, or the themes from each interview can be recorded separately and drawn together into a consolidated table at the end.

The themes become subordinate or super-ordinate. It is not necessarily the regularity of a themes appearance from the interviews that decides if it should be selected as super-ordinate or identified as being more important than another theme. It is how a theme might inform other parts of an individual's account, and the richness it offers, that should be considered.

### **5.2.1. Recruitment of the participants**

The participants were recruited from a purposive sample group that was identified from the caseload of individuals open to the Learning Disability Community Specialist Health Services.

Inclusion criteria included individuals with a mild learning disability; who were over eighteen years of age; had the capacity to consent; with a diagnosed psychotic illness and in recovery; and were able to communicate with spoken English language. Exclusion criteria included anyone that was unable to consent to take part in the research, had difficulties with spoken language and that did not have a learning disability.

Clinicians, a health care professional who works as the primary caregiver, within the Learning Disability Community Specialist Health Team, were requested to identify individuals who would meet the inclusion criteria and could be interested in participating in the research. The clinician was provided with an information sheet (Appendix 14) which gave all the research details and information on their involvement in the recruitment process for the research. If the clinician agreed to take part in the research, they were asked to complete a consent form (Appendix 15).

When a potential participant was identified, the clinician was asked to give their professional judgement on whether the individual was well enough to be involved in the research, to reduce any likelihood of distress. The clinician was asked to ensure that the individual had a diagnosis of psychosis and they were in recovery, based on their knowledge of the person; they would be able to talk about their psychotic experiences without becoming upset; they were not currently experiencing any psychotic symptoms; they would be able to recall their last episode of psychotic illness, based on the time-frame of their remission; and had the capacity to consent.

The clinician was asked to discuss the research with the potential participant during their usual clinical contact time and to provide them with an Easy Read information sheet (Appendix 16) and a carer/support worker information sheet (Appendix 17). The carer/support worker information sheet was provided to inform the participants support network on all the relevant details of the study, in case the participant wanted to discuss the research with them.

If the potential participant agreed to take part in the research and gave consent for their contact details to be shared with the researcher, the clinician was asked to complete a referral form so the researcher had all the relevant contact information (Appendix 18). They were also asked to inform the potential participant that the researcher would contact them within two weeks of the referral, to allow the potential participant time to go through the information sheet again and to be able to contact the researcher if they had any further questions.

After two weeks, the researcher contacted the potential participant to discuss the research and the possibility of them taking part. If they still agreed to be involved in the research a date and time, convenient to the participants, was arranged for an interview. The participant was able to choose either attending a clinic appointment or for the researcher to visit them at the location of their choice. If they chose to attend a clinic appointment transport was arranged, where required. They were also informed, if they chose to, that they could bring someone along to support them during the interview. An appointment letter was then sent to the participant to confirm the planned arrangements for the interview (Appendix 19). If they declined to be involved in the research, at this point, the participant was informed that all their contact details would be destroyed.

After the participant had agreed to take part in the research and an appointment letter had been sent out. The clinician was then asked to complete a data collection form (Appendix 20). The data collection form required the clinician to provide a description of participant's psychotic clinical presentation, in relation

to the individual's thoughts, feelings and behaviours that they experienced when they were mentally ill. This information was used to make a comparison against the individual's interview content to ascertain if the description of their lived experiences enhanced the understanding of their clinical psychotic presentation. If the clinician did not know the details of the person's psychotic presentation they were requested to record 'not known', or 'NK', in the corresponding section of the form.

### **5.2.2. Participants**

There is no 'right' sample size in qualitative research (Sargeant, 2012; Smith and Osborn, 2003; Sandelowski, 1995), however, most IPA literature recommends a small sample ranging from individual case studies to ten participants. As this study's focus was on in-depth interviews a sample size of ten participants was proposed.

Sixteen individuals, with a learning disability, had shown an interest in taking part in the research. However, four individuals declined further intervention during the initial contact. Therefore, their contact details were destroyed.

A total of twelve individuals were invited to take part in an interview. Out of these twelve individuals, two elected to attend a clinic appointment and indicated they did not require transport to be arranged for them, but they did not attend the appointment. They were once again contacted, to ask if they would like to rearrange, but they selected to withdraw from the research at this point. Once again, their contact details were destroyed.

Of the ten remaining participants, six chose to undertake the interview within their own home and four chose to attend a clinic appointment. Only one individual wanted to be interviewed without support, the remaining nine all chose to be accompanied. One participant was supported by a social care worker, two by a parent, and six by a community nurse.



During the interview, one participant was able to undertake the first stage of the sort-card exercise but started to become increasingly anxious. As it was noted that they were experiencing a degree of distress the interview was terminated. They were asked if they wanted to suspend the interview until another time or if they wanted to withdraw from the research altogether. They chose to withdraw from the research. The researcher ensured that they were offered support after the interview by a staff member that knew them well. It was later reported that the participant was able to return to their usual activities and was not affected by taking part in the research. All the data collected were destroyed, and they were removed from the research.

This gave a total of nine participants, with a learning disability, who undertook the research. A brief pen picture of the nine participants is given below. Pseudonyms have been used to preserve the participant's privacy. Any information that might identify them has been changed. All other third-party names have also been altered or not used.

### **Paul**

Paul is a 43-year old gentleman who lives in his own tenancy, with 24-hour support from a social care agency. His mother passed away five years ago. He has regular contact with his father and his siblings. Paul has a diagnosis of learning disability, cyclical hypomania and epilepsy. He enjoys going out to the cinema and bowling. He attends a breakfast club and a crafts club at the weekend.

### **Sally**

Sally is a 26-year old lady who lives with both her parents and her sister. Sally has a diagnosis of learning disability, psychosis and depressive disorder. She enjoys working in a charity shop one day a week, attending activities with her personal assistant and listening to music on her Kindle. She has a close relationship with her grandparents.

**Robert**

Robert is a 40-year old gentleman who lives independently in his own tenancy. Robert has a diagnosis of learning disability, psychotic disorder and emotionally unstable personality disorder. His father passed away five years ago and has few friends, so he relies on carers for company. He enjoys talking to people on the telephone. He is a heavy smoker and consumes alcohol throughout the day.

**Linda**

Linda is a 58-year old lady who lives independently in her own tenancy. She receives support from a social care agency and her family network. She has a diagnosis of learning disability, psychosis, emotionally unstable personality disorder, epilepsy and numerous physical health conditions. Linda has three children who are now adults and have families of their own. She enjoys spending time with her large family and accessing community activities.

**Jim**

Jim is a 30-year old gentleman who lives at home with his parents and sister. He has a diagnosis of learning disability, attention deficit hyperactivity disorder, autism, psychosis and diabetes. He receives fourteen hours social care support a week, divided into three and a half hours over four days. He enjoys attending the gym with his sister.

**Keith**

Keith is a 35-year old gentleman who lives independently in his own house. He has a close relationship with his brother, who provides two to three hours support a day. He has a diagnosis of learning disability, schizophrenia and paranoid psychosis. Keith is a member of a local church and enjoys attending services and church social activities.

**Paula**

Paula is a 31-year old lady who lives alone. She has two children aged eight and nine. Her children have recently been removed by social services and they

are currently in the care of Paula's parents. Paula receives 16-hours a week paid support from her mother. She has a diagnosis of learning disabilities, epilepsy, emotionally unstable personality disorder, psychosis and micro chromosomal deletion.

### **Tilly**

Tilly is a 45-year old lady who lives independently in her own home. She is married but she and her husband do not live together. Her husband visits several times a week and helps her with chores. Tilly has a diagnosis of learning disability, depression, post-traumatic stress disorder and psychosis. She enjoys visiting her mother and sister and has regular visits from her brother.

### **Sam**

Sam is a 58-year old gentleman. He lives independently in a flat and does not receive any social care support. He has a diagnosis of learning disability, alcohol induced psychosis, alcohol dependency and bowel cancer. Sam spends the majority of his time socialising with others in public houses.

The demographics of the participants are shown in table 7 below

No.	Name	Age	Gender	Co-morbid diagnosis	Supported by family carer	Supported by paid carer
1.	Paul	43	Male	Cyclical hypomania Epilepsy	No	Yes
2.	Sally	26	Female	Psychosis Depressive disorder	Yes	No
3.	Robert	40	Male	Psychotic disorder Emotionally unstable personality disorder	No	Yes
4.	Linda	58	Female	Psychosis Emotionally unstable. Personality disorder	No	Yes
5.	Jim	30	Male	Attention deficit hyperactivity	Yes	No

				disorder Autism Psychosis		
6.	Keith	35	Male	Schizophrenia Paranoid psychosis	No	Yes
7.	Paula	31	Female	Epilepsy\Emotionally unstable personality disorder	No	Yes
8.	Tilly	45	Female	Depression Post-traumatic stress disorder Psychosis	No	Yes
9.	Sam	58	Male	Alcohol induced psychosis Alcohol dependency Bowel cancer	No	No

Table 7: Demographics of participants

### 5.2.3. Structure of the interview schedule

Consistent with IPA, data was gathered through face-to-face interviews using a semi-structured schedule and the sort-card tool. The interview was conducted in three parts. Stage one involved asking the participant three set questions. Stage two, involved the participants selecting their own psychotic symptoms from the sort-card tool. Stage three involved placing the selected symptoms into a timeline. Particular care was taken to ensure that the interview would not be too burdensome and that participants would have support for any stress that may have arisen. As all but one of the participants had elected to be supported by someone they knew well, there was a confidence that the individual's supporter would be able to recognise if the individual became unduly distressed. In addition, an emphasis was placed on the fact that the participant, or their supporter, could end the interview at any time without reprisal. For the participant who chose to be interviewed alone, the researcher paid particular attention to their non-verbal communication during and after the interview, to assess for any distress if it occurred.

At the start of the interview the participants and any supporting individuals, were welcomed and thanked for attending. A general introduction and small talk took place, to establish a friendly atmosphere until both parties were relatively comfortable. All individuals were asked if they understood the research aims and what it entailed and if they wanted another copy of the information sheet. The participants were then introduced to a consent form (Appendix 21). Each sentence on the consent form was either read by the participant or read out to them. If they agreed with the sentence they were asked to place a tick in the corresponding box. After reading all the sentences within the consent form the participant was once again asked if they wanted to continue with the interview. If they agreed they were asked to sign the bottom of the consent form. As part of the consent, participants were also asked if the interview could be audio taped. It was explained that the audiotape would only be listened to by the researcher and the recording was to enable the interview to be transcribed, thus avoiding a need to take notes. All participants agreed to this request.

#### **Part one: Set questions.**

A set of four questions were typed, in large font, onto individual A4 sheets of paper and laminated. The participant was shown each prompt card in turn and the question was read out to them. These questions were used to ascertain if the participant could recall and describe the details of their psychotic illness experience without the need for any reminders.

Each participant was asked:

**Question 1:** *“Can you tell me about the time when you are mentally ill/ have psychosis?”*

(The terminology was altered accordingly to reflect participant’s language set).

**Question 2:** “Can you tell me how you felt?”

**Question 3:** “Can you tell me what you thought?”

**Question 4:** “Can you tell me how you behaved?”

The participant was allowed time to answer the questions. They were then asked if they had any questions of their own and if they were happy to continue.

### **Part two: selecting individual psychotic symptoms**

The participants were then shown three prompt cards. These were laminated A4 sheets of paper. One had the word 'yes' typed in large font with a large tick underneath it and the background was coloured green. One had the word 'no' typed in large font, with a cross underneath it and the background was coloured red. The final sheet of paper had the words 'don't know' typed in large font, with a question mark underneath it, with no additional colour added (Illustrated in figure 15).

This colour system was used as PWLD are familiar with, and have been exposed to, similar colour-coded systems as they are routinely used within the learning disability service. The participant was then introduced to the card-sort tool. It was explained to them that each card contained a sentence that described a single symptom of psychosis, accompanied by a Widgit symbol.

<b>Yes</b>	<b>No</b>	<b>Don't know</b>
<b>✓</b>	<b>X</b>	<b>?</b>

Figure 15: Prompt cards

They were asked to look at each of the sort-cards in turn. They were instructed to consider the statement and to decide if they had ever experienced the symptom. If they had experienced the symptom they were asked to place the sort-card on top of the 'yes' card. If they had not experienced the symptom, they

were asked to place the sort-card on top of the 'no' card. If they were unsure, did not know, or could not remember, they were asked to place the sort-card on top of the 'don't know' card. All participants were asked if they were happy to do this or if they would prefer the sentence to be read out to them. All of the participants chose for the cards to be read out to them. As identified in Zentel *et al's* (2007) research, having text, symbols and speech could heighten the participant's understanding and recognition of the presented material. They were once again asked if they were happy to continue with the exercise and if they had any questions.

Each statement on the sort-cards was read out to the participant. They were given time to consider if they had experienced the symptom or not and the statement was re-read to them if required. When all of the fifty-four statements had been read out and placed on the 'yes', 'no', or 'don't know' piles they were told that they had gone through all the symptoms. They were then asked if they were satisfied with their choices and if they would like to go through any cards again.

The participants were then asked if they would re-visit the 'don't know' cards again, in case they could recall experiencing any of the symptoms. They were then thanked for undertaking the first part of the exercise and acknowledged for being able to remember their symptoms.

### **Part three: time-line exercise**

For the third part of the exercise, the prompt cards and the rejected sort-cards were removed, and they were asked to re-look at the cards that they had placed in the 'yes' pile. Two additional prompt cards were introduced, to form a timeline. These were laminated A4 sheets of paper. One had an arrow pointing upwards and the word 'first' typed at the top of the page, the other had an arrow pointing downwards and the word 'last' printed at the bottom of the page. The participants were asked to once again go through all the selected sort-cards, but on this occasion, they were asked to consider which symptoms came first,

or at the beginning of their illness and which of the symptoms they experienced just before or during a full psychotic episode.

Each individual sort-card was once again read out to the participant. They were then given time to consider where in their illness they experienced the symptom and to place it in a continuum on the timeline. As the participants went through the selected sort-cards they could, if required, reposition previously positioned sort-cards, either up or down the timeline, depending on where they felt the symptom occurred. When they had placed all the sort-cards in a timeline they were asked if they were satisfied with the order they had positioned the sort-cards in and if they wanted to re-position any. The sort-cards were then read out again from the first symptom on the timeline to the last symptom and the participants were once again asked if they concurred with the order they had placed the sort-cards in. If not, they were asked to alter the arrangement until they were satisfied that they had placed all the sort-cards in the correct order. Once the participant had agreed to the final order of the sort-cards a photograph was taken to record the exact position. Illustrated in figure 16 and 17.



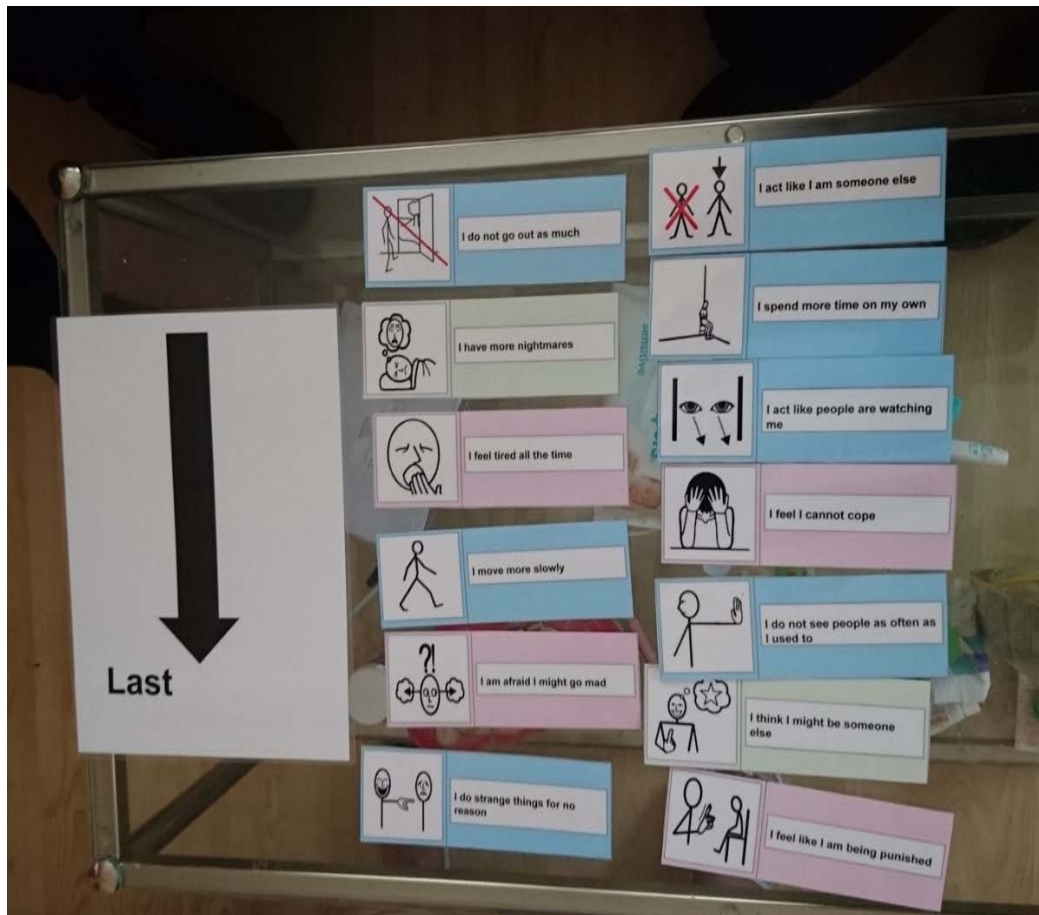


Figure 16: Sort-card exercise.

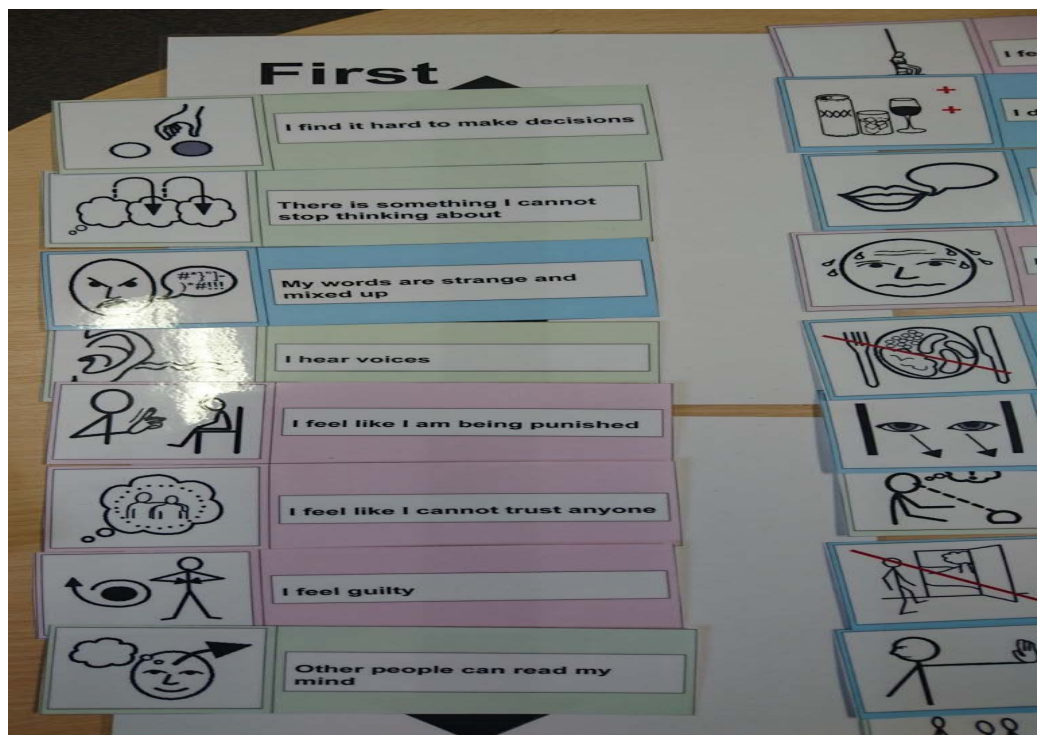


Figure 17: Sort-card exercise

It was then explained to the participants that, for the majority of individuals who suffer from a psychotic illness, they experience the same things, in the same timeframe, on every relapse. Therefore, the order in which they had placed their experienced symptoms would be the order they would most likely experience their symptoms again if they were to relapse. Thus, their individual timeline, or relapse signature, could help them, and those that support them, to recognise when they were starting to relapse, enabling them to seek timely support. The participants were given the option of their symptom timeline be written into a relapse signature (or support plan, care plan, index signature plan, depending on the terminology the participant preferred). All participants said that they would welcome the opportunity of having their individual relapse signature information recorded into a Care Plan. Therefore, it was agreed that this would be typed up and posted to them.

The participants were thanked for their time.

### **5.3. Data collection**

The primary concern of IPA is to elicit rich, detailed and first-person accounts of experiences and phenomena under investigation. The Easy Read card tool, which formed the schedule of the semi-structured interviews, was particularly suited to IPA methodology as it was able to support PWLD to explore and discuss their individual interpretation of their psychotic symptoms by concentrating on thoughts, feelings and behaviours (Pietkiewicz, 2014).

The interviews were recorded on a digital recorder in order to take advantage of higher quality recording. The audio recordings were subsequently labelled with the corresponding pseudonym. The audio recordings were transferred onto an encrypted NHS computer and password protected.

The photographs of the sort-card timeline were taken with a digital camera on an encrypted NHS mobile telephone. Following the interview, the photographs

were coded with a corresponding pseudonym name to the audio recording and saved within the same password protected file, on an encrypted NHS computer.

## **5.4. Data analysis**

Each audio recording was transcribed with a verbatim record of the interviews, capturing pauses and non-verbal content, such as laughter. The accuracy of all the transcripts was checked by reading them while listening to the recording. In some transcripts, the participant's speech was not always clear and there were a few instances where some words or sentences were inaudible. This was reflected in the transcript by placing, [inaudible], in place of the inaudible word or sentence. This occurrence was not regular enough to have an adverse effect on the overall quality of the interview data. All names and places were replaced by using '\_\_\_\_\_'. Emphasised words were underlined, and capital letters were used if the participant raised their voice or shouted.

There was a technical difficulty with participant nine's audio recordings and the final section of part three of their interview did not record. The recording was transcribed up to the point where the tape ended. As a photograph had also been taken of the participant's chosen sort-cards there was a record of their timeline, which was used to extract the data required.

The assumption in IPA is that the analyst is interested in learning something about the respondent's psychological world (Smith, 2003). The meaning is central, and the aim is to try to understand the context and complexity of the meanings not the frequency they are said. To achieve this, the researcher engages in an interpretative relationship with the transcript. Therefore, it is recommended that the researcher totally immerses themselves in the data and tries to step into the participant's shoes, as far as possible.

Smith *et al.*, (2009) and Smith, Flowers, and Larkin (2009) outline a number of stages involved in data analysis and these were used to help guide the process.

The initial stage involved an idiographic approach, by listening to the audio recording and close reading of the transcripts a number of times, with the left-hand margin used to annotate interesting responses from the participant. The transcript was then read twice again, paragraph by paragraph, to enable immersion of the data and engagement of the participant's account. Each separate reading, and listening to the co-recording, provided some new insights. This process was followed for all nine transcripts.

The next stage involved reading the transcript again, using the other margin to document emerging titles, notes were made on the left-hand margin of the transcript to record initial impressions and comments on the data, on a very exploratory level. There are no rules on what to comment on, but focus was on three key areas: descriptive- focusing on content; linguistic comments-selecting on specific use of language; and conceptual- asking questions of the data and moving forwards to a more conceptual understanding of the participant's descriptions of their psychotic symptoms, and what was important to the participant. In this conceptual level, notes were also made of any additional comments the participants made about their experiences. This process aimed utilise the hermeneutic circle, in formulating a concise phrase at a slightly higher level of abstraction, allowing the part to be interpreted in relation to the whole. In addition, and in keeping with Smith (2003) the entire transcript was treated as data and no attempt was made to omit or select particular passages for special attention. It was noted that there were numerous themes being identified, but Smith (2011) advocates this can reflect the richness of data.

In the next stage, an initial chronological list was made of emergent themes. Then, a more analytical, or theoretical ordering, was undertaken in an attempt to make sense of the connections. There were themes that immediately clustered together, whereas others emerged as superordinate concepts, described by Smith, *et al.*, (2009) with the analogy of a magnet, with some of the themes pulling others in to help make sense of them. A final list comprised of numerous superordinate themes and subthemes.

The forth step involved searching for connections across emergent themes, mapping how emergent themes fitted together and identifying common links between them by using the concepts of abstraction (similar themes brought together), subsumption (emergent theme becomes subordinate theme), numeration (frequency in which theme is supported signifies importance) and function (what function it serves).(Smith and Osborn, 2008). Each theme was typed into boxes, so similar or related subordinate themes could be grouped together. Although some themes fitted together as created concepts there was a recognition that each individual's experience is unique and therefore may not fit into pigeon-holed themes. Although commonalities were identified, it is important to bear in mind the divergences between the participants, ensuring ideograph and phenomenological dimensions of the research were not lost.

The same process was repeated with each transcript. Although an attempt was made to keep each transcript separate there was a recognition that it was inevitable that there would be a degree of influence from the previous transcription with the themes from the first transcript helping to orient the subsequent analysis.

In the final stage, the themes were re-examined to gain an overall picture and to identify any super-ordinate and sub-ordinate themes. Through this process individual emergent and sub-ordinate theme were relabelled and reconfigured. Deciding on the themes to focus on required prioritising and preference was given to richness of descriptions and illumination of the psychotic symptoms. The super-ordinate and sub-ordinate themes are identified in table 9 in Chapter 6.

## **5.5. Findings**

Evaluation of the sort-card exercise revealed that all the participants, except one, had identified a similar number of symptoms to elicit their experiences, illustrated in figure 18.

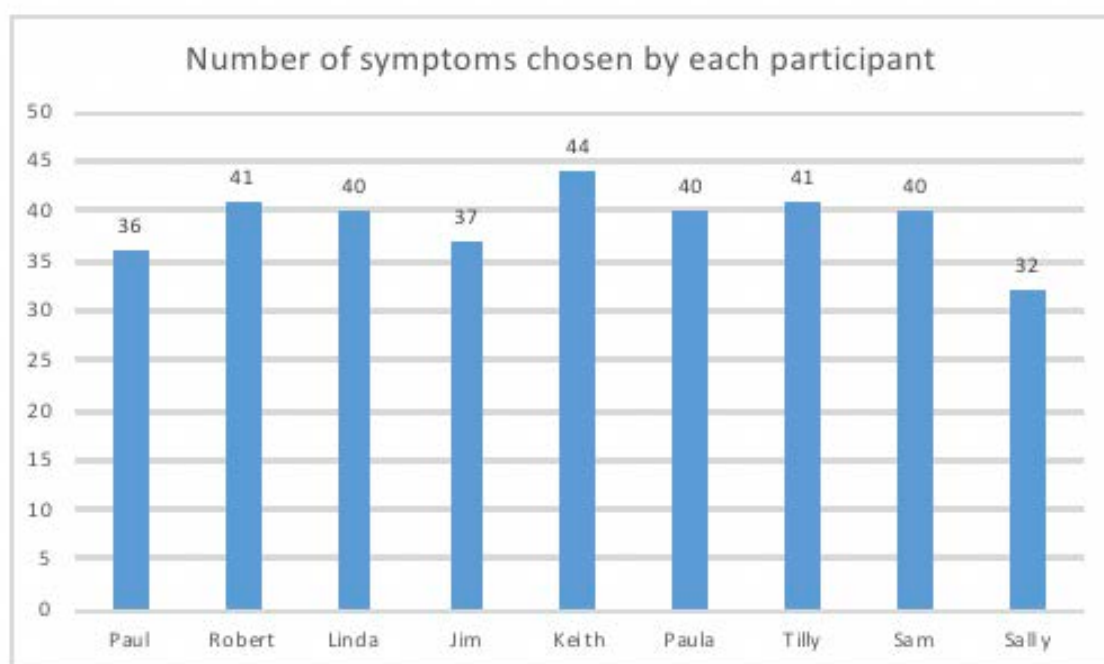


Figure 18: Total amount of symbols chosen by each participant

Sally was the only participant that had difficulty identifying her individual symptoms and required the support of her carer to frame and label both her symptoms and the order in which they developed for her.

Paul asked if his individual symptoms could be produced in the style of Picture Exchange Communication (PECS) cards (Appendix 22a). The sort-cards were therefore printed in squares, laminated, and hole punched in the top left-hand corner, so the cards could be joined with a split ring.

In addition to the symptoms within the sort-card tool some participants identified their own bespoke symptoms. Sally, identified four additional symptoms, being *'listening to music with no sound'*, *'co-ordination difficulties'*, *'vomiting'*, and *'being obsessed with death and dying'*. Tilly's additional symptoms were, *'I stop answering calls and texting people'*, *'I get hot and sweaty'*, *'I feel pain in my body'* and, *'I stop answering the door'*. Linda said that she will, *'go to bed'*. Whereas, Jim said, *'I get upset and talk to myself'* and *'keep coming up and down stairs'*. Paul described *'eating more'*, *'sleep walking'*, and *'making impulse*

*purchases*'. These additional psychotic statements were added to the participant's Care Plans and a Widgit symbol was sourced to support the statements.

Some participants described certain psychotic symptoms being present all the time, even in relapse, or that they experienced the symptom throughout their psychotic illness, from the prodromal stage to full psychosis. They described experiencing a symptom at the being of their illness, but the intensity of the symptom increased as their illness progressed. This was reflected in their Care Plan.

Linda, with the support of her community nurse, was able to identify areas that might keep her well, such as having a regular sleep pattern and eating healthy. She asked if an additional column could be added to her Care Plan, so these protective factors could be recorded alongside her symptoms. Therefore, an extra column was therefore added to her Care Plan entitled, '*what helps me*'. (Appendix 28a).

Table 8 (overleaf) offers a summary of each participant's chosen symptoms and the total times each symptom was selected. An in-depth analysis of the findings from Study 2 is presented within Chapter 6.

**Table 8: results from sort-card selection for each participant**

	Paul	Sally	Robert	Linda	Jim	Keith	Paula	Tilly	Sam	Total
Behaviour	1	2	3	4	5	6	7	8	9	
Difficulty sleeping	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
My words are strange and mixed up	✓		✓	✓	✓	✓	✓	✓	✓	8
I talk or smile to myself		✓	✓	✓		✓	✓	✓	✓	7
I act like people are watching me				✓	✓	✓	✓	✓	✓	6
I do strange things for no reason			✓		✓	✓		✓		4
I spend more time on my own			✓		✓	✓		✓		8
I don't take care of how I look any more		✓	✓	✓	✓		✓	✓		6
I act like I am someone else			✓	✓	✓	✓	✓	✓		6
I don't see people as often as I used to	✓	✓	✓	✓	✓		✓	✓		8
I don't eat as much		✓	✓		✓		✓		✓	5
I don't go out as much	✓		✓	✓	✓	✓	✓	✓	✓	8
I don't do what people ask me to do	✓	✓	✓	✓	✓		✓	✓		7
I drink more			✓	✓					✓	3
I smoke more			✓				✓			2
I move more slowly	✓	✓		✓		✓		✓	✓	6
I can't sit still for long	✓				✓	✓	✓	✓	✓	6
I get angry a lot more	✓	✓	✓	✓	✓	✓	✓		✓	8



	Paul	Sally	Robert	Linda	Jim	Keith	Paula	Tilly	Sam	Total
Thoughts	1	2	3	4	5	6	7	8	9	
My thoughts are racing	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
My senses seem better	✓	✓			✓			✓		4
I think I have special powers	✓						✓		✓	3
I can read other people's minds						✓			✓	2
Other people can read my mind			✓			✓				2
I get messages from the TV	✓					✓			✓	3
I have strange feelings in my body	✓		✓			✓	✓			4
There is something I cannot stop thinking about	✓	✓	✓	✓	✓	✓	✓	✓		8
I think I might be someone else			✓	✓		✓		✓		3
I can see things other people cannot see		✓	✓	✓		✓	✓	✓	✓	7
I think people are talking about me		✓	✓	✓	✓	✓	✓	✓	✓	8
I think people are against me	✓	✓	✓		✓	✓	✓		✓	7
I have more nightmares	✓	✓	✓	✓		✓	✓	✓	✓	8
I cannot concentrate	✓		✓	✓	✓	✓	✓	✓	✓	
I think very strange things	✓	✓	✓	✓	✓	✓	✓		✓	8
I hear voices	✓	✓	✓	✓		✓	✓	✓	✓	8
I think someone controls what I think	✓	✓	✓	✓	✓	✓	✓		✓	8
I think a part of me has changed shape		✓		✓		✓			✓	4
I find it hard to make decisions	✓		✓	✓	✓	✓	✓	✓	✓	8

	Paul	Sally	Robert	Linda	Jim	Keith	Paula	Tilly	Sam	Total
Feelings	1	2	3	4	5	6	7	8	9	
I feel helpless	✓		✓	✓	✓	✓	✓	✓		7
I'm afraid I might go mad	✓	✓		✓	✓	✓	✓	✓	✓	8
I feel sad	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
I feel anxious	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
I feel more religious		✓				✓	✓			3
I feel like I am being watched			✓		✓	✓	✓	✓	✓	6
I feel I am on my own	✓		✓	✓	✓	✓	✓	✓	✓	8
I feel tired all the time	✓	✓		✓	✓	✓	✓	✓	✓	8
I feel confused	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
I feel I am forgetting things	✓		✓	✓	✓	✓			✓	6
I feel strong and powerful	✓									1
I feel far away, in a different world	✓	✓		✓	✓	✓		✓	✓	7
I feel like I can't cope	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
I feel like I am being punished			✓	✓	✓	✓	✓	✓	✓	7
I feel like I cannot trust anyone	✓		✓	✓	✓	✓	✓			6
I feel like I do not need to sleep	✓	✓	✓			✓		✓	✓	6
I feel guilty			✓	✓		✓		✓	✓	5
I feel irritable	✓	✓	✓	✓	✓	✓	✓	✓	✓	9

## 5.6. Conclusion

The focus of the second part of the research was to utilise a sort-card tool with PWLD, to help them report their experiences of psychosis and their individual symptoms. Nine participants were interviewed using a semi-structured framework and the sort-card tool developed in Study 1. The interviews were conducted in three parts, with set questions used within part one. In parts two and three the participants were asked to use the sort-card tool, to identify their individual psychotic symptoms and then to advance to produce a structured timeline of illness progression. The interviews were audio recorded and photographs were taken of the timeline exercise. The timeline helped to inform the participant's Care Plan.

What became clear from undertaking this exercise is the value of the sort-card tool and how it provided the participants with a vehicle to articulate their psychotic experiences, as never before. The symptom statements, together with the Widgit symbols, invited and facilitated individuals to narrate and validate their experiences. The sort-card tool enabled the participants to recognise, frame and label their psychotic symptoms. The term 'Emotional Intelligence' was created by two researchers (Mayer *et al.*, 2001), and further popularised by Dan Goleman in his book of the same name (Goleman, 2006). In the same way that emotional intelligence has been coined to describe an individual's ability to recognise their own and other's emotions, discern between different feelings and label them appropriately and to use emotional information to guide thinking and behaviour, the researcher found that the sort-card tool empowered the participants to have a '*symptom intelligence*'. This symptom intelligence galvanised the participant's ability to recognise their own symptoms, label them appropriately and use them to guide a relapse signature.

The upcoming chapter will discuss the findings of Study 2 and its implications for further research.

## **Chapter 6: Findings from Study 2**

### **6.1. Introduction**

Interpretative Phenomenological Analysis (IPA) enabled the consideration of the data to stay close to the things that matter to the participants (Larkin and Thompson, 2012) representing the phenomenological aspects of the interviews undertaken in Study 2. The data was interpreted, not as a single process, but as it evolved from close engagement with the participants, with an aim to capture the discourse of the lived experience.

This chapter details the findings from Study 2, which involved the implementation of a sort-card tool, to ascertain if it could enhance the reporting of psychotic symptoms for PWLD. Nine participants were interviewed as part of the research. The interviews were conducted in three parts. Stage one involved asking each participant four set questions, stage two involved the participants selecting their own psychotic symptoms from the developed psychotic symptom sort-card tool and stage three involved the participants placing the selected symptoms into a timeline. (Appendix 22b to 30b).

In conjunction with the interviews, clinicians from the local learning disability service, who had referred the participants to the study, were asked to provide a description of participants psychotic clinical presentation, in relation to the individual's thoughts, feelings and behaviours that the participant had experienced when they were mentally ill.

Initially, this chapter focuses on the findings from part one of the interview, which explored the participant's ability to describe their experiences in their own words. Each participant will be discussed in turn giving the clinician's description of the individual's psychosis and the participants own descriptions.

The next section of this chapter conveys the super-ordinate themes and the corresponding sub-ordinate themes, listed as A to D within table 9, which were identified from the nine interviews. The super-ordinate themes were present in the majority of the interviews, whilst the corresponding sub-ordinate themes have a greater variability and may not be pertinent for all participants.

The final super-ordinate theme, listed as E within table 9, will be discussed last. This part of the chapter is derived from part three of the interview where the participants developed an individual timeline of their psychotic symptoms.

**Table 9: Super-ordinate and sub-ordinate themes**

<b>A</b>	<b>Understanding sort-cards</b>	
	A1	Widgit symbols
	A2	Asking for further clarification
	A3	Literal understanding
	A4	Other relevant data
<b>B</b>	<b>Additional symptoms</b>	
	B1	Eating
	B2	Sleeping
	B3	Physical changes
	B4	Changes with activities
	B5	Smiling and talking
	B6	Withdrawal
	B7	Other additional experiences
<b>C</b>	<b>Underlying causes</b>	
	C1	Trauma
	C2	Hope and despair
<b>D</b>	<b>Additional symptom description</b>	
	D1	Feelings and emotions
	D2	Visual hallucinations
	D3	Auditory hallucinations

	D4	I feel more religious
	D5	I have strange feelings in my body
	D6	I think a part of me has changed shape
	D7	Difficulty sleeping
	D8	I think I might be someone else
	D9	There is something I can't stop thinking about
	D10	I feel far away, in a different world
	D11	I act like people are watching me
	D12	Individual symptom descriptions
<b>E</b>	<b>Timeline</b>	
	E1	Symptoms all the time
	E2	Grouping symptoms
	E3	Thoughts, feelings, and behaviours
	E4	Individuals timelines

## 6.2 Part one of the interviews: symptom reporting

After initial introductions and an explanation of Study 2, the participants were introduced to four questions. These questions were used to determine if the participants could recall and describe the details of their psychotic illness experience without the need for any prompts. The terminology was altered accordingly to reflect participant's language set.

Each participant was asked:

**Question 1:** *"Can you tell me about the time when you are mentally ill/ had psychosis?"*

**Question 2:** "Can you tell me how you felt?"

**Question 3:** "Can you tell me what you thought?"

**Question 4:** “Can you tell me how you behaved?”

For many of the participants verbalising their experienced symptomology was difficult.

Paul was seen in a clinic environment and was supported by a social care support worker. His clinician reported Paul had been given a diagnosis of hypomanic episodes. The clinical picture revolved around a behavioural presentation with descriptions of property damage, verbal and physical aggression, throwing objects, trying to stab others with pieces of glass, and self-harming behaviours of hitting and scraping his hands along walls. The clinical description alluded to feelings in the form of anxiety but there was no reference to any of Paul’s thoughts.

When asked, Paul described his psychosis as “*having a breakdown*” (Appendix 22b, line 174) and linked his presentation to his grief over his mother’s death and abuse from a previous social care provider. He described feeling angry, which resulted in him displaying behaviours that challenged services, such as throwing water at people (Appendix 22b, line 5) and setting fire to paper (Appendix 22b, line 9).

Sally attended a clinic appointment accompanied by her mother, Joyce. Sally’s clinical description offered a diagnosis of psychotic episodes with relapse and a depressive disorder. The clinical picture offered a description of Sally’s thoughts, which included voice hearing, olfactory and gustatory hallucinations and rumination over death. It also described behavioural changes such as screaming, staring episodes, repeated hand washing, praying and laughing to herself. There were no descriptions of how Sally would be feeling during her psychotic illness.

Joyce described Sally experiencing two-weekly cyclical mood changes (Appendix 23b, line 472) and made links to Sally’s psychotic presentation with

another family member who suffered from bipolar affective disorder. Sally was unable to offer any description of her psychotic illness apart from her describing feeling angry. She predominately said, "*I have no idea*", and relied on Joyce to describe her presentation.

Robert attended a clinic appointment with his community nurse. Robert had been diagnosed with a psychotic disorder, together with an emotionally unstable personality disorder. The clinician's description was unable to yield any details of how Robert felt or thought during his psychotic episodes, as the clinical report only contained behavioural observations. These observations included self-harming behaviours such as drug overdoses, cutting, and attempting to jump off a bridge, together with self-neglect and excessive smoking and drinking habits.

When asked about his psychotic experiences Robert described himself as suffering from paranoid schizophrenia (Appendix 24b, line 80) but felt that his personal description of his psychosis was often ignored. He elaborated by saying, "*although the doctors don't think I do, they think I imagine it, but I know when I hear voices*" (Appendix 24b, line 82). He had some understanding of his thoughts, feelings, and behaviours and was able to describe hearing voices, a symptom with which he portrayed as needing help with (Appendix 24b, line 38). When asked about his feelings he said, "*I feel like a lunatic*" (Appendix 24b, line 42). Robert's other symptom descriptions revolved around his behavioural presentation which paralleled the clinical description. He described excessive drinking of alcohol, which he explained helped him sleep. He also described "*cutting up*" (Appendix 24b, line 6) and continued by saying, "*I can't stop cutting up*" (Appendix 24b, line 52), head-banging, hitting himself, and "*kicking off - smashing things*" (Appendix 24b, line 52).

The researcher interviewed Linda in her own home, supported by her community learning disability nurse. Linda has a diagnosis of psychosis and emotionally unstable personality disorder which has resulted in multiple psychiatric hospital admissions. Her clinical depiction focused on her self-harming behaviours including drug over-doses, putting a plastic bag over her



head, numerous ligature attempts, the ingestion of liquids, and attempts to jump into a river.

When asked about her thoughts, feelings and behaviours Linda identified herself as suffering from mental health difficulties but could only describe hearing voices.

Jim elected to attend a clinic appointment, supported by his mother, Susan. Jim has a diagnosis of attention deficit hyperactivity disorder, psychosis, and autism but the clinical report was unable to give a description of his psychotic presentation.

Jim described his illness as depression. He articulated his thoughts during his illness period as being directly associated with him being unable to concentrate. He described feelings of sadness and being upset and irritable, whereas, he described his behaviours as him suffering from panic attacks and repeatedly asking questions.

Keith was visited at home with the support from his community learning disability nurse. Keith's clinical portrait gave a diagnosis of paranoid schizophrenia with relapse due to bereavement. His clinical description was only able to offer a limited description of his presentation in respect of his thoughts, which included Keith thinking he was being watched and that he had experienced poor sleep hygiene.

Keith described himself as being paranoid and referred to his psychosis as his "*episodes*" (Appendix 27b, line 144). He stated, "*it's like fighting myself all the time*" (Appendix 27b, line 154) and "*I have arguments with myself, in my head*" (Appendix 27b, line 9). He also described a behavioural presentation of shaking, hitting himself, an inability to leave the house, becoming aggressive, and cutting himself. He said, "*I find it hard to understand it*" (Appendix 27b, line 16).

Paula was also interviewed within her own home, supported by her community learning disability nurse. Her diagnostic profile includes pseudo-hallucinations due to levels of stress, epilepsy, emotionally unstable personality disorder and micro-chromosomal deletion. The clinical description did not include any of Paula's feelings. It described her thoughts of command auditory hallucinations from God. Her behavioural description detailed self-harming behaviours in the form of drug over-doses and ligature attempts.

When asked to describe her thoughts, feelings, and behaviours Paula narrated a detailed picture. She described seeing men with half a face, covered in blood. She also said, *"The voice tells me I'm going to be like them, and it only goes away if I self-harm"* (Appendix 28b, line 8). When asked, she imparted that the voice belonged to a female called Kate. Paula said that she felt scared and was able to depict a direct link of her auditory hallucinations to her behavioural presentation, acknowledging that the command hallucinations resulted in her cutting herself and that she was too scared to sleep.

Tilly chose to be interviewed at home with support from her community learning disability nurse. Tilly has a diagnosis of depression, psychosis and post-traumatic stress disorder. Her clinical depiction did not detail any symptoms relating to her feelings and only described a presentation of nasty sinful thoughts about herself which resulted in poor sleep and social withdrawal.

When asked, Tilly was unable to label her psychotic illness and just described covering herself with a blanket when she became poorly.

Sam chose to be interviewed at home without any support. Sam has a diagnosis of alcohol-induced psychosis, alcohol dependency and bowel cancer. Sam had quite a detailed baseline of psychotic symptoms within his clinical picture, but once again this did not include any of Sam's feelings. His thoughts were described as auditory hallucinations, from a Mrs Brown and a Michael Clayton, who told him to call other people names or these voices would shoot

his body with pellets or spread rumours about him. The clinical picture also described him as having third-person auditory hallucinations with running commentary and thoughts that people on the street can hear what the voices were saying to him. The clinical report also detailed Sam's behavioural presentation with self-harming behaviours, self-neglect, aggression towards others and non-compliance with medication. Sam himself was only able to describe hearing voices.

### **6.3. Super-ordinate themes and corresponding sub-ordinate themes from part two of the interview**

In part two of the interview, the participants were shown three prompt cards containing the words 'yes', 'no' and 'don't know'. The participants were then introduced to the sort-card tool, developed within Study 1, as set of cards each containing a single symptom of psychosis, accompanied by a Widgit symbol.

The participants were asked to look at each of the sort-cards in turn and to consider if they had ever experienced the symptom or not. Each statement on the sort-card was read out to the participant and placed on the corresponding prompt card depending on their response.

#### **6.3.1 Super-ordinate theme A: Understanding the sort-cards**

Each sort-card psychotic statement had been simplified and was supported by a Widgit symbol. The Widgit symbol had been added to the sort-card to aid the understanding of the psychotic statement as, for people who have reading difficulties, images are an important cue to what words might be saying. Tilly clarified that the simplified statements enhanced her ability to understand her symptomology. She said, *"I think the words are better, I do feel this way, I have to be honest"* (Appendix 29b, line 335)

As all but two of the participants were unable to read, they were given the option of the sort-card being read out to them. All the participants chose to have the cards read out to them. As the sort-cards were read out they were shown to the participant. With some of the participants both the words and the related Widgit symbol was not understandable, but they were able to understand and recognise the symptom when it was read out to them.

#### **6.3.1.1. Theme A1: Widgit symbols**

All of the participants found the supplementary Widgit symbol a useful addition to the sort-cards. Sally had particular difficulty describing her symptom experience, even with the sort-cards to prompt her, and relied heavily on Joyce to describe her psychotic illness for her. However, she did relate to the Widgit symbols as a prompt. For example, she looked at a symbol of a bed which accompanied the statement for difficulty with sleeping and was able to decipher the inferred meaning.

As described previously, Paul was accustomed to using symbols and sentences in the form of Picture Exchange Communication System (PEC). This system is predominately used for individuals who have little or no communication abilities to help them communicate with pictures. As he had previously found this system useful, he specifically requested that his individualised psychotic symptom Care Plan was produced using this format, with the Widgit symbols being placed within the centre of the card and the statement written underneath it.

When Robert viewed the sort-card describing anxiety he started to laugh. He had identified with the Widgit symbol, which depicted a face with beads of sweat. He said, *“I get like that, all sweaty”* (Appendix 24b, line 162).

Although Tilly was one of the participants that could read she specifically requested that the Widgit symbols were included in her individualised Care Plan. When asked if she would prefer to just have the words she said, *“No, the*

*symbols help as well*" (Appendix 29b, line 407). Her community learning disability nurse went on to say that she thought the symbols would help Tilly explain her symptomology to her psychiatrist and to her family members (Appendix 29b, line 463 and 470).

#### **6.3.1.2. Theme A2: Asking for further clarification**

Although the psychotic statements had been simplified as much as possible, there was a degree of ambiguity for some of the participants, especially in regard to the more abstract concepts. During the interviews some participants asked for further clarification on the meaning of the statements. For example, Robert asked for an explanation of the two statements, *'My thoughts are racing'* and *'I feel confused'*. Jim asked for an explanation of the statement *'I see things other people cannot see'* and Tilly requested more information on the statement *'I get messages from the television'*. In part two of the interview, Tilly had indicated that her senses appeared to be better, but it wasn't until part three of the interview, during the sort-card exercise, that she asked for further clarification on the meaning of the statement. Once a further description was offered she stated, in a loud voice, *"oh, that's at the top"* (appendix 29b, line 264), referring to the statement being one of her early psychotic illness symptoms.

#### **6.3.1.3. Theme A3: Literal understanding**

Two of the participants had difficulty understanding the psychotic symptomology that had a more abstract concept, resulting in them interpreting some of the psychotic statements within the sort-card tool literally. For example, the statement, *'I don't go out as much'* relates to a reduction in a person accessing community services and community participation. When Jim was asked if this statement related to him during his psychotic illness he stated, *"I normally go out every day, to take the stuff down to the recycle bin"* (Appendix 26b, line 108). Paul also had a literal understanding of some of the statements. When asked whether he ever felt strong and powerful he replied, *"One day I threw a bucket of water on \_\_\_\_\_"* (Appendix 22b, line 187).

#### **6.3.1.4. Theme A4: Other relevant data**

Although the participants were able to independently identify which pile the symptom sort-card should be placed, *yes*, *no* or *don't know*, some participants made frequent checks with the individuals that were supporting them at the interview to endorse the choices they had made. In particular, the participants that were supported by a parent asked for clarification of their experiences. For example, Sally asked Joyce directly for support by saying, "*You can answer it*" (Appendix 23b, line 178) and Jim asked his mother, "*Have I ever mentioned nightmares, or if I have them?*" (Appendix 26b, line 54).

The sort-cards enable the participants to have a greater understanding of their symptomology. For example, in using the sort-cards it was evident that Paula had been able to gain further clarity into the breadth and depth of her psychotic symptoms, with her saying, "*There are lots of things, I didn't realise how much things, I didn't realise*" (Appendix 28b, line 276). Whereas, Keith was able to identify that poor sleep patterns were a troubling symptom for him and requested additional Easy Read information on sleep hygiene after the interview.

#### **6.3.2. Super-ordinate theme B: Additional symptoms**

All the participants identified noticeably more symptoms that related to their individual psychotic presentation when they utilised the sort-card tool compared to part one of the interview, where they had been asked to recall their experiences from memory alone. In addition, as the participants began to recognise the symptoms they had experienced, they were also able to articulate a more in-depth description of some bespoke symptoms that were not included in the sort-card tool. Some of these additional symptoms had a common theme across participants, including sleep, eating, and physical changes, categorised in the themes below.

#### **6.3.2.1. Theme B1: Eating**

The sort-card tool described the symptom of eating less but three of the participants described changes in appetite that were different to this original statement. Sally and Paul said that they started to eat more as their psychotic illness progressed and Robert reported that he would stop eating altogether.

#### **6.3.2.2. Theme B2: Sleep**

Both Paul and Sally reported changes within their sleep pattern that were not included within the sort-card tool. Sally described early morning awakening, whereas Paul articulated that he began to suffer from sleepwalking behaviours.

#### **6.3.2.3. Theme B3: Physical changes**

As part of their personal symptomology, some participants described experiencing physical changes. Tilly said that she experienced pain. Tilly, Robert and Jim talked about being hot and sweaty. Keith recalled how his Tourette's traits worsened in line with his psychotic presentation and Sally reported vomiting and co-ordination difficulties.

#### **6.3.2.4. Theme B4: Changes with activities**

Sally, Jim and Tilly all reported changes to their activities. When shown the sort-card statement '*I do strange things for no reason*' Joyce (mother) described how Sally would listen to music with no sound. Jim related the sort-card that described an inability to sit still with him constantly walking up and down stairs and Paula felt that this statement described her pacing. Both Tilly and Sally described how their activities were disrupted by an alteration in their perception of time. Sally was described with catatonic features and Tilly stated that she would lose a sense of time.

#### **6.3.2.5. Theme B5: Talking and smiling to myself**

When shown the sort-card statement '*I talk or smile to myself*' both Tilly and Jim could relate to this behaviour but felt that their experiences were slightly different to the statement on the sort-card. They both stated that they would talk

to themselves but would not smile. Jim elaborated further by stating, *“Sometimes I might laugh to myself, think of funny things in my head”* (Appendix 26b, line 106).

#### **6.3.2.6. Theme B6: Withdrawal**

In describing her early onset symptoms Tilly talked about withdrawing from others by not answering the door or the telephone to callers and she would also stop texting other people. Whereas, Jim recalled barricading himself in his bedroom, by putting items of furniture behind the bedroom door.

#### **6.3.2.7. Theme B7: Other additional experiences**

There were a number of other symptoms that participants described that were unique to them and could not be separated into a sub-ordinate theme. Jim reported refusing to take his medication and becoming verbally abusive. Joyce described how Sally would regress to her childhood and attempt to go to school. Paul talked about making impulsive purchases and participating in gambling behaviours. He said, *“...and you know that when I went to the seaside, I gambled on the machines when they was with me....it was more than ten pound”* (Appendix 22b, line 293).

Paula had a strong reaction to the sort-card statement *‘I feel like I am being punished’*. She shouted, *“I’d say, yes that’s true”* (Appendix 28b, line 115) and went on to make reference to being punished by others and God several more times throughout the interview. She also corrected the statement which described thoughts of other people talking about her, by saying *“they are”* (Appendix 28b, line 111). She reported that although she did not necessarily think that her words were strange and mixed up or that she repeated herself, other people reported to her that she had been observed displaying these behaviours.



### 6.3.3. Super-ordinate theme C: Underlying causes

It was evident from the analysis of the data that some participants related their psychotic symptoms to traumatic events in their lives. There was also a feeling of despair from some participants, implying the journey to recovery had been a difficult one.

#### 6.3.3.1. Theme C1: Trauma

A theme of trauma was identified for a number of participants. Paul was particularly traumatised by previous events that he directly attributed to a deterioration in his mental state and his presentation of inappropriate behaviours. As he started to use the sort-card tool he began to discuss his psychotic symptoms and the events that had preceded his psychotic illness. It became evident, as the interview progressed, that these life events were multifaceted and interconnected. He described how he had suffered financial and psychological abuse from his previous carers, portraying how he felt they had, *“Let him down”*, (Appendix 22b, line 15) and had stolen his money, *“they used to pinch money out of my bank card”* (Appendix 22b, line 58). He narrated how his mother had passed away and his carers had not allowed him to attend the funeral. This, in turn, caused him to display behaviours that were challenging. As his actions become more difficult to manage his relationship with his family started to break down. He said, *“I tried to go back to me dad and they kept bringing me back to that place.....and another time my brother and sister don’t want nothing to do with me now”* (Appendix 22b, lines 54 and 74). He went on to describe how his further decline in his mental health led to him being involved with the police. He directly related his traumatic experiences to an array of behavioural changes, describing himself as experiencing a *“break down”* (Appendix 22b, line 174).

Robert described experiencing physical abuse from his parents, which he directly linked to him suffering from nightmares and his need to consume alcohol to help him sleep. He stated, *“Like when I were a little boy and my dad*

*would smack my sister a lot and punch her around the place. And I used to see that. And it plays on my mind"* (Appendix 24b, line 263). He also described him being the victim of a robbery and since this incident carrying a knife with him, saying, *"Ya, known, since I've been robbed I carry it [knife] now with me....so, I can show me blade and they piss off then."* Robert was also able to describe that he felt unsupported by public services and associated their lack of support as indicative that they did not care about him. As he began to talk about his psychotic symptoms he recognised that he had experienced auditory hallucinations for many years. He said, *"And I went for years, I've been having this since I were a baby, voices in me head. It tookay me til now to admit I did that on purpose because I was poorly"* (Appendix 24b, line 88). Robert also showed signs of unresolved bereavement, as he related some of his psychotic symptoms directly to his father's death. When asked if he had ever experienced the symptom of not being able to stop thinking about something he said that he thought about his father every day and that he thinks he may be like his father.

Sally described her isolation and lack of social networks directly relating to her poor recovery profile.

Keith also described bullying and physical violence towards him as a trigger for his mental illness. He recollected, *"Yea....I've been beaten up that many times I can't feel nothing....It's ever since I've been bullied when I was young.....I just got held off a gang where I used to live, and they used to beat the shit out of me on a regular basis"* (Appendix 27b, lines 464 and 476).

#### **6.3.3.2. Theme C2: Hope and despair**

The participants were able to articulate how their psychosis had had a direct effect on their resilience to cope, with some participants identifying that they used poor coping strategies to reduce the impact of their symptoms.

Joyce recalled how Sally's initial psychotic presentation had had a slow prodromal stage and her anguish in trying to obtain support and an explanation

for her daughter's mental decline. Robert described using alcohol as a means of aiding sleep and smoking heavily to cope with the daily demands of his illness. He reported, "*Like today, I've already smokayed one hundred fags today*" (Appendix 24b, line 386). Paula found identifying her symptoms challenging and described herself as feeling stupid. When she completed the sort-card tool exercise she looked at her selected symptoms and said, "*Why is it all yes?*" (Appendix 28b, line 103).

However, Keith did have a degree of positivism about his recovery journey. Although he described his experiences as, "*being a long battle*" (appendix 27b, line 300) he implied that he was now on the road to wellness. Tilly also recognised that her current treatment was efficacious, saying, "*I mean to be honest with you I can't remember when I last felt this way. Erm, I sleep well and I don't sleep during the day....I'm sleeping right through because I used to wake up*" (Appendix 29b, line 453).

#### **6.3.4. Super-ordinate theme D: Additional symptom descriptions**

During part two of the interview, the participants not only identified the psychotic symptoms that related to them, but they were able to offer further unprompted descriptions of their experiences activated by the statement on the sort-card.

##### **6.3.4.1. Theme D1: Feelings and emotions**

Six of the participants identified negative feelings, such as frustration, anxiety, and nervousness associated with their psychotic experiences. Paul, Sally, Sam and Robert all described feelings of anger. Sam said that he got angry at his auditory hallucinations. Robert said that he would particularly become angry as his psychosis worsened and he was unable to meet the demands placed on him by other, explaining, "*When people want me, gets me angry all the time*". (Appendix 24b, line 525). Keith also acknowledged that the symptoms of his psychosis were difficult to manage and related it to his ability to accomplish his

daily living skills, affirming, *"I feel I can't cope..... I get to the suicidal stage"* (Appendix 27b, line 198). Joyce also described Sally as being angry and volatile. Linda recalled how her psychosis resulted in isolation, with her saying, *"I feel very lonely sometimes"* (Appendix 25b, line 123).

#### **6.3.4.2. Theme D2: Visual hallucinations**

Four of the participants were able to explicitly describe their experiences of visual hallucinations. Paula struggled to understand her visual hallucinations and reported that she often asked others why they could not see what she was seeing as her hallucinations caused her a great deal of distress. She reported seeing men with half a face, with blood running down the faces causing her to be too scared to sleep. Keith recognised that he could see things other people could not see and explained that he will often see *"dead people"* (Appendix 27b, line 406). Sally was reported to respond to her visual hallucinations, for example, she would attempt to leave the house to greet people she thought she could see outside and would make a bed up for a boy that she reported seeing. She also said that she could see eyes in walls. Tilly described her visual hallucinations as, *"I see shadows and faces and things.....it's not a proper face, it's like, smoky....shadows, like somebody is behind me"* (Appendix 28b, lines 427 and 445).

#### **6.3.4.3. Theme D3: Auditory hallucinations**

Five of the participants were able to describe hearing voices that they would often respond to. Sam said that his sleep was affected as he could hear voices talking to him throughout the night and he could often hear ringing in his ears. Sally's voices would tell her to go outside or she could hear them coming from her handbag. Paul said he would get messages from the television programme The Bill. Keith also stated that he would hear voices *"that wouldn't shut up"* (Appendix 27b, line 396) and that he would get messages from the television and from the walls, saying *"Yea, that's funny that int it?"* (Appendix 27b, line 414). Paula described hearing someone talking into her ears but not

understanding what was being said, she stated, *"I hear them, sometimes I don't understand what language it is"* (Appendix 28b, line 441).

#### **6.3.4.4. Theme D4: I feel more religious**

Keith talked about hearing voices from God and described God as being, *"The Boss"*. Paula said that she had got a bible when she became ill and thought this was because God was punishing her. Sally also started to become more religious as her psychotic symptoms deteriorated and would pray more. She also started to become obsessed with death and dying.

#### **6.3.4.5. Theme D5: I have strange feelings in my body**

Two participants were able to elaborate on strange feelings in their body, with Paula describing increased pain and Paul describing being *"all knotted up"* (Appendix 22b, line 158).

#### **6.3.4.6. Theme D6: I think a part of me has changed shape**

Paul, Sally and Keith all gave an additional description for the sort-card statement that described a part of them had changed shape, which they all linked to gaining weight. Sally reported feeling ugly and fat and Keith described the need to weigh himself on a regular basis.

#### **6.3.4.7. Theme D7: Difficulty sleeping**

All the participants reported difficulties with their sleep patterns as a symptom of their psychosis, with four participants offering additional descriptions on how this symptom affected them. Sam reported that he was unable to sleep as voices kept him awake. Keith said that he could go days without being able to sleep and Paula expressed she was scared to sleep. Tilly reported that she would often wake up during the night with a feeling *"like someone is shaking me"* (Appendix 29b, line 457).

#### **6.3.4.8. Theme D8: I think I might be someone else**

Three participants related to the sort-card statement 'I think I might be someone else' as part of their psychotic symptoms. Robert related this to his father and explained that he would often dress up in black clothing. Paula described feeling like someone else, that would control her, and Keith said, "*I see myself as a different person*" (Appendix 27b, line 108)

#### **6.3.4.9. Theme D9: There is something I can't stop thinking about**

Keith described himself constantly ruminating over the past, whereas, Tilly concurred that she experienced this symptom but said she "*didn't know what it was*" (Appendix 29b, line 68) that she was thinking about.

#### **6.3.4.10. Theme D10: I feel far away, in a different world**

Both Keith and Paula describe feeling far away and in a different world, with Paula recounting her experience akin to being lost and confused. Whereas, Keith explained his experiences, as if he was living in two worlds.

#### **6.3.4.11. Theme D11: I act like people are watching me**

When asked about acting like people are watching them, Paula, Jim and Tilly were able to elaborate on their experiences. Paula said that people were following her, and Tilly said that she thought people were also watching her and talking about her when she was out. Jim was more specific and described being watched when he went to the gymnasium.

#### **6.3.4.12. Theme D12: Individual symptom descriptions**

During the sort-card exercise, there were a number of symptoms that the participants were able to elaborate on by describing their individual experiences that fell out of being categorised into a sub-ordinate theme. Sally linked her olfactory hallucinations to the sort-card statement '*my senses seem better*' and described how her smell and taste were heightened. She would often complain about being able to smell and taste things that others could not, such as smelling smoke. Paul recalled how he would forget to do things and gave the

example of forgetting to turn the oven off. Robert recognised that his consumption of alcohol increased as his psychotic symptoms worsened. He illustrated this with various comments:

*“I hit the drink to help me sleep”* (Appendix 24b, line 108).

*“When I am by myself, I do hit the drink quite a lot.....I make sure I have quite a few and then get me head down, and it help me to sleep then if I try to sleep without drink I can’t sleep”* (Appendix 24b, lines 100 and 108)

*“but I drink two percent alcohol.....I don’t drink the highest volume”* (Appendix 24b, lines 102 and 106).

Paula thought that the voices gave her special powers. When she described her special powers she said, *“My brain has, or she has [Kate], I’ve got two brains”* (Appendix 28b, line 68). Keith elaborated on the sort-card statement *‘I think something controls what I think’* by explaining that he was fighting demons all the time. When asked if the demons controlled his thoughts he replied, *“Yea, yea, they do actually”* (Appendix 27b, line 94). He also described standing in his neighbour’s gardens for the symptom statement *‘I do strange things for no reason’*. Sam also reported that he thought other people could read his mind, especially doctors.

### **6.3.5. Super-ordinate theme E: Timeline**

In part three of the interviews, the participants were asked if they could arrange their chosen symptom statements into a timeline, with the first symptoms that they experienced being placed at the top of the timeline and the last symptoms at the bottom. This was to ascertain if they were able to develop a unique individualised relapse signature. This part of the interview proved the most challenging aspect of the exercise as the participants were relying on memory recall at a time when their perceptions were often impaired which is often difficult for PWLD. Some participants required the assistance of their support worker to help them undertake this exercise.

However, both Tilly and Jim appeared to find this part of the interview quite cathartic and readily moved the sort-cards up and down the timeline, positioning them and repositioning them, until they had them all in the correct position. As Tilly undertook the timeline exercise she was able to recall additional symptomology that was not included in the sort-card tool, together with adding additional descriptive information to her chosen sort-card statements. The timeline appeared to help her crystallise her psychotic symptoms further and added benefit to the symptom identification exercise within part two of the interview. Jim was also able to recognise the timing of when he would self-administer his pro re nata (PRN), or as required psychotropic medication, in an attempt to reduce or stop his symptoms from progressing.

#### **6.3.5.1. Theme E1: Symptoms all the time**

Five of the participants, they were unable to place all their symptoms in a timeline as they described experiencing the symptoms all of the time or all through their psychotic episode. Paul felt that all of his identified symptoms were present from the beginning of his psychotic illness and therefore was unable to complete a timeline. Both Sally and Robert felt that some of their symptoms were present at the start of their illness, and remained with them throughout their psychotic illness, with these initial symptoms gradually getting worse. Though Paula did not describe her initial symptoms worsening at the time of onset, she did explain that as her symptoms developed they remained with her, getting steadily worse. She described seeing things that others cannot see, ruminating and pressured thoughts, and hearing voices as particularly troublesome. Keith reported experiencing a number of symptoms, including hearing voices, being watched and thinking people were against him, on a daily basis, regardless of the presence of any psychosis.

#### **6.3.5.2. Theme E2: Grouping symptoms**

All of the participants had difficulty placing some of their experienced symptoms in a linear timeline. They were able to identify where in their psychotic illness the symptoms appeared, for example at the beginning or the middle, but felt



that a number of symptoms developed at the same time. Therefore, they grouped the statements together on the timeline. For example, Tilly described her experiences as “*being similar.....it all comes in one*” (Appendix 29b, lines 329 and 331).

#### **6.3.5.3. Theme E3: Thoughts, feelings and behaviours.**

Common warning signs of a psychotic illness may include insomnia, difficulty concentrating, and increased paranoia and hallucinations, with many of the early symptoms being related to thoughts and feelings, rather than behaviours.

Although it is recognised that a direct comparison cannot be made between the participants, as each participant has a unique collection and timing of psychotic symptoms, this theme highlights the similarities of thoughts, feelings, and behaviours identified by all the participants.

It was evident from part one of the interview that the participants had difficulty framing and labelling their individual psychotic experiences, with most of the described symptoms relating to a behavioural presentation. Without a tool to give them the words to describe their psychotic experiences they struggled to find the language needed to provide an embodiment of their psychosis.

In using the sort-card tool the participants were able to report the experience of a number of psychotic symptoms from all three symptom areas of thoughts, feelings and behaviours. However, the symptoms relating to feelings were the most prominent experience across all participants. Out of the sort-cards statements, the participants identified a total of 107 behavioural symptoms, 104 thought symptoms and 123 feeling symptoms.

All the participants reported the behavioural symptom of difficulty with sleeping. They all identified with the thought symptom of having racing thoughts. All the participants described the symptom of feeling sad and anxious, feeling confused, feeling like they were unable to cope and feeling irritable.

For the thought symptomology, eight of the nine participants reported auditory hallucinations, paranoia and thought disorders. A smaller number of participants reported the more abstract concepts such as thinking that they could read other people's minds, other people reading their mind, thinking they were someone else, and thinking that their body shape may have changed.

Within the behavioural symptomology, eight of the nine participants reported being angry and that their words were strange and mixed up. They also reported social isolation with a desire to spend more time on their own or not wanting to see others as often as they usually would. The lowest reported symptoms within this section were linked with increased smoking and alcohol consumption.

Eight out of the nine participants reported feeling afraid that they might go mad, feeling on their own and being tired all the time. The next most reported symptoms within this category were feelings of helplessness, memory difficulties, feelings of being far away, a perception of being punished and being unable to trust anyone. The least chosen symptoms within this category were the feeling of being more religious and feeling strong and powerful.

Paul identified 36 symptoms, of which 13 were behaviours, 14 were feelings, and nine were thoughts.

Sally identified 32 symptoms, six of which she described as residual symptoms, which she experienced all of the time. Her initial presentation was identified with behaviour symptoms, such as eating less and spending more time on her own. As her psychosis progressed she began to experience paranoid thoughts and visual hallucinations.

Robert identified both feeling and behaviour symptoms in his initial presentation. He identified 41 symptoms in total, with changes in thought perceptions, such

as paranoia and auditory hallucinations developing as he experienced florid psychosis.

Linda identified 40 symptoms, having a mix of thoughts, feelings and behaviours from the beginning of her psychotic episode to the end of her illness.

Jim identified 37 out of the 54 symptoms available. He reported that his prodromal symptomology mainly consisted of feelings of irritability, being confused and feeling sad, with behavioural changes appearing towards the latter part of his illness.

Keith identified 44 symptoms, seven of which were there all the time. He also reported that his primary symptoms mainly consisted of feelings, with some changes in thought perception, with behavioural symptoms developing much later in the illness progression.

Paula felt that she suffered from 40 symptoms, with 22 of these materialising at the beginning of her psychotic episode and remaining with her throughout, increasing in intensity. She pinpointed a combination of thoughts, feelings, and behaviours throughout her illness.

Tilly felt that she had a total of 41 symptoms, with four of which were additional symptoms to the sort-card tool. She also had a mixture of thoughts, feelings and behaviours throughout her psychotic illness, but behavioural symptoms were the dominant presentation towards the end of her illness.

Sam recognised 40 symptoms, with him only experiencing 11 behavioural symptoms throughout his entire illness.

Out of all the 54 sort-cards, each statement was chosen at least once by one participant.

#### **6.3.5.4. Theme E4: Individual timelines.**

No two persons experienced the same psychotic symptoms in the same order. For one person, their initial symptom could be insomnia, for another, it could be social withdrawal. Knowing and identifying the symptoms that are specific to the individual and where the symptoms develop within the individual's psychotic illness, is important, as it allows for the early identification of relapse. This theme emerged from the participant's individual timelines, that were enhanced by using the sort-card tool.

In analysing the data from the timeline exercise all the additional symptoms that the participants had identified, together with the symptoms that were reported to be experienced all the time were removed. The data from Paul's psychotic symptom Care Plan was also removed as he was unable to distinguish if his psychotic experiences followed a timeline.

In examining the behavioural symptoms, three participants felt that changes in their sleep, eating and levels of anger were an indication that they may be becoming mentally unwell. Four participants described social withdrawal occurring as their illness progressed. Whereas, four participants recognised that they lost interest in how they looked, with six behaving as if they were someone else occurring within the active stage of their psychosis (see figure 19)

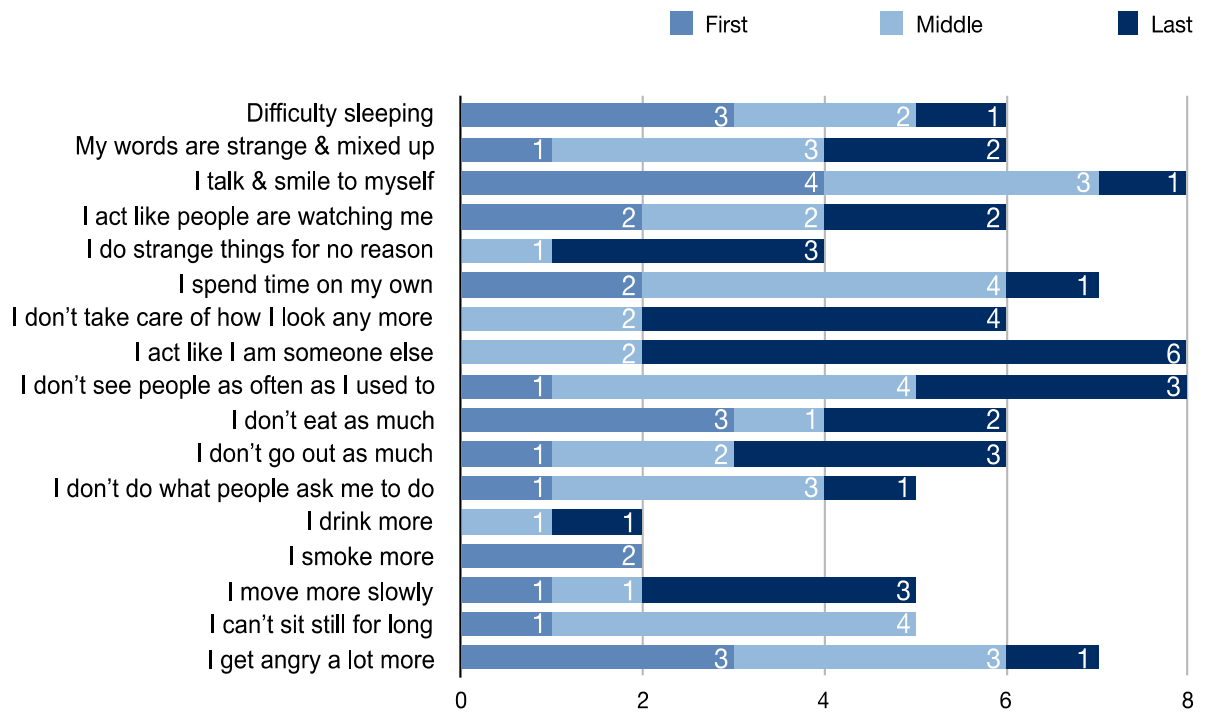


Figure 19: Number of chosen behavioural symptoms

For the thought symptoms (see figure 20) four of the participants described experiencing racing thoughts, difficulty with decision making and being unable to stop thinking about something within the middle stage of their illness. This was coupled with three participants feeling that they were unable to concentrate. A significant number of participants described experiencing nightmares within the active stage of their illness, which can be linked as all participants described difficulty with sleep within the behavioural symptoms.

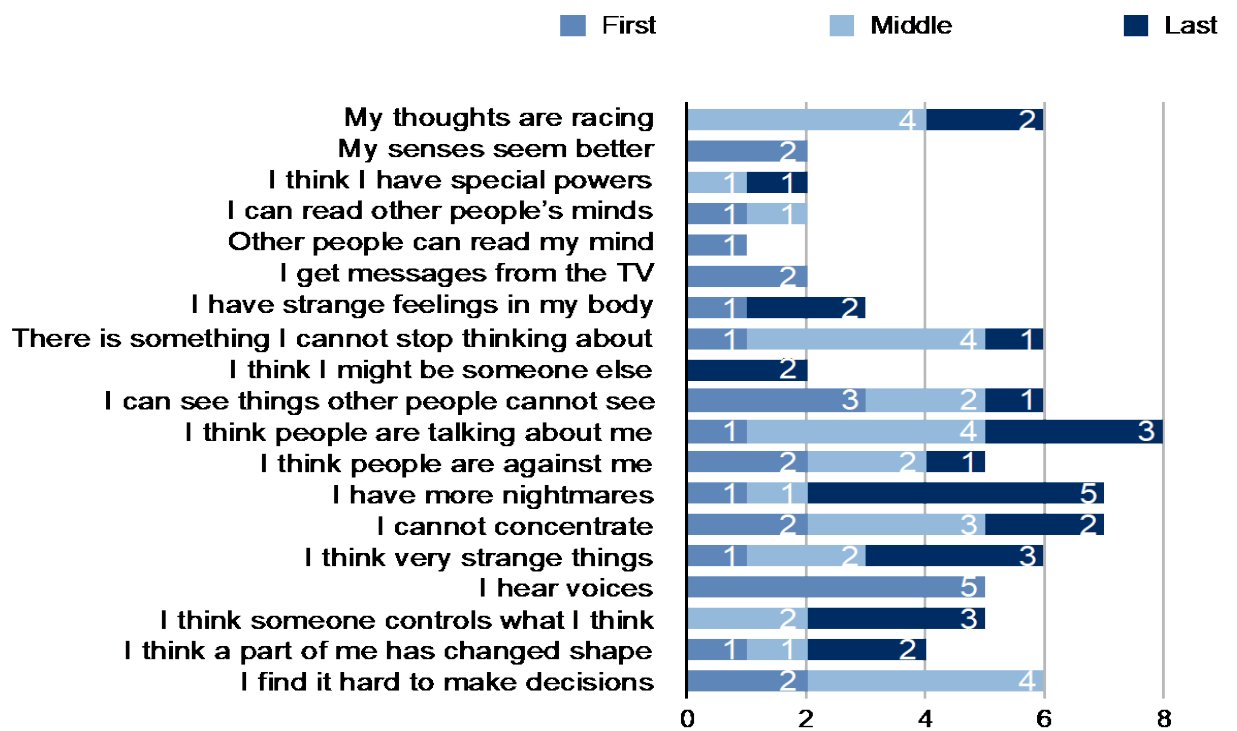


Figure 20: Number of chosen thought symptoms

The largest reported symptoms of feelings revealed that a high percentage of the participants experienced negative emotions, such as feelings of helplessness, sadness, and anxiety, all within the early stages of their psychotic illness. As their illness developed into the active stage some participants felt that they were forgetting things, that they were far away, in a different world, and that their ability to cope was greatly reduced (see figure 21).

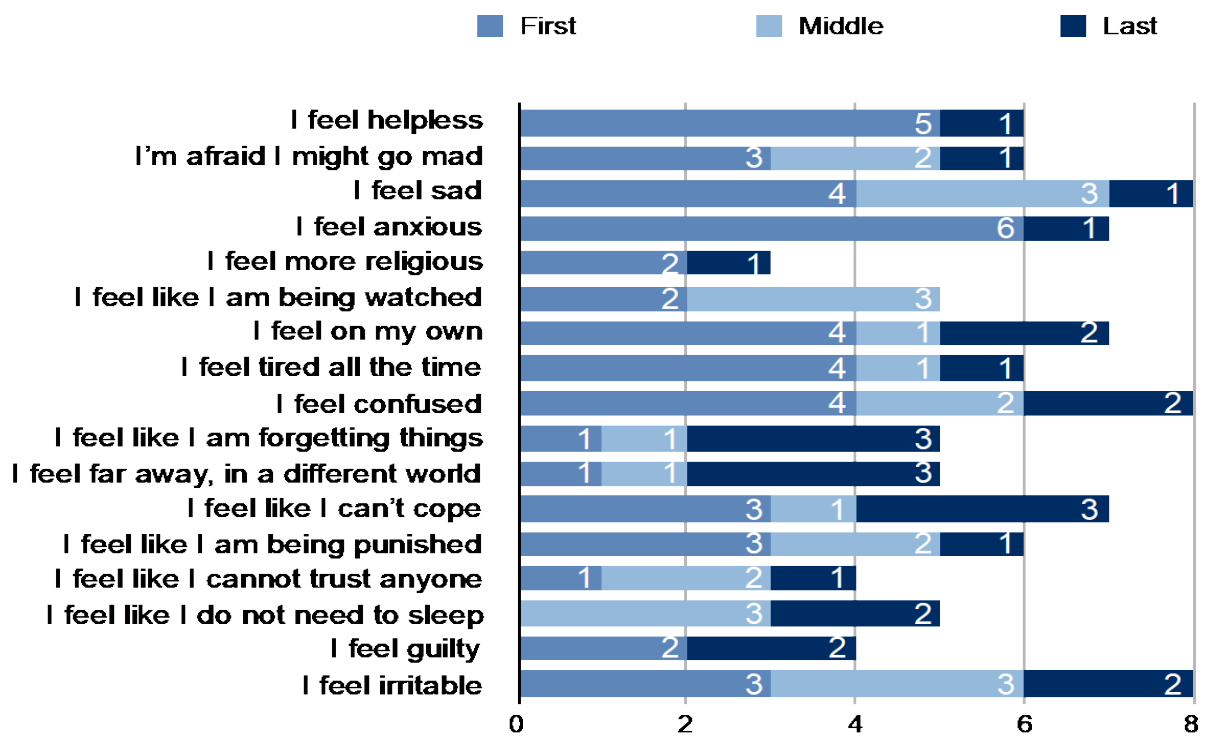


Figure 21: Number of chosen feeling symptoms

## 6.4. Conclusion

All of the participants were able to undertake all three stages of the interview process in differing degrees. Within part one of the interview it was evident that both the participants and the clinician had difficulty identifying the full range of psychotic experiences.

The introduction of an Easy Read psychotic symptom sort-card tool enabled the participants to label and frame their individual experiences and, in doing so, empowered them to narrate a detailed description of their psychotic symptomology. They were not only able to distinguish their own experiences of their psychotic illness but some of the participants were able to give a more enriched description that supported the psychotic statement on the sort-cards. Armed with a detailed description of their individual symptoms the participants went on, within stage three of the interview, to identify their individual timeline of

symptoms that developed within the prodromal and active stages of their psychosis.

The upcoming chapter will briefly discuss the preliminary planning stage, followed by the findings and a discussion of Study 1, before discussing the findings from Study 2 and its implications within the clinical arena.



## Chapter 7: Discussion

### 7.1. Introduction

The purpose of this research was to explore if people with learning disabilities (PWLD) can report their own psychotic experiences. The research consisted of two interlinking studies, supported by some preliminary planning, illustrated in figure 7.

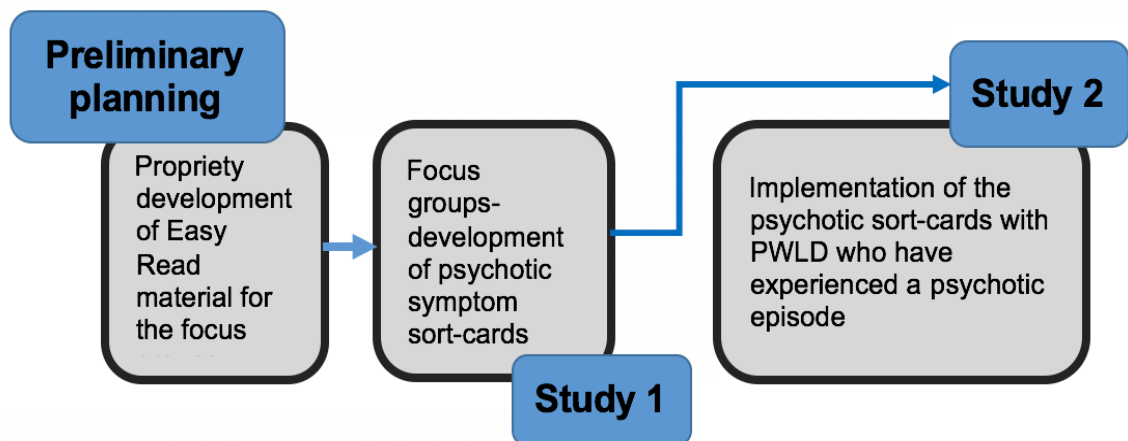


Figure 7: The study design

The objectives for the two interlinking studies were:

**Study 1:** Developing an Easy Read psychotic symptom sort-cards tool.

1. To explore and identify with PWLD an appropriate symbol that matches a description of a symptom of psychosis.
2. To use the chosen symbol together with the symptom description to create a set of Easy Read sort-cards.

**Study 2:** Implementing and evaluating the Easy Read psychotic symptom sort-cards tool.

3. To explore if the Easy Read sort-cards can enhance the reporting of psychotic symptoms for people with mild learning disabilities

This chapter will initially offer a brief summary of the preliminary planning stage, followed by the findings and a discussion of Study 1.

Following this, and in keeping with the phenomenological essence, the chapter will then go on to capture the uniqueness of individual participant's experiences in relation to their psychosis and the emerging super-ordinate themes that developed from Study 2. In this section, a brief resume of the theme will be offered, together with a recap of the findings before inference from the super-ordinate themes will be considered. Finally, the discussion will reflect on the implications for clinical practice.

## **7.2. Preliminary planning**

Preliminary planning was undertaken to enable effective implementation of a number of focus groups which were then implemented within Study 1. It is generally acknowledged in the literature that communicative abilities are the most significant barrier to successfully conducting focus groups with PWLD (Kiernan, 1999; Prosser and Bromley, 1998; Stalker, 1998). In an attempt to overcome this barrier, the material to support the focus groups was adapted into an Easy Read format. The Easy Read format enabled all the focus groups to follow a similar structure so that the information was presented consistently and that the terminology and ideas under discussion were offered in a way that could be understood by PWLD.

The preliminary planning involved utilising fifty-four psychotic symptom statements from Birchwood *et al.*'s (1995) research, that centred around identifying and managing an individual's psychotic relapse signature. The statements were simplified by using the Flesch Reading Ease Formula

(Readability Formulas, 2016). The Easy Read statements were then paired with two 'best-fit' symbols that had the greatest representation for each of the statements. Full details of the preliminary planning are discussed in Chapter 3.

### **7.3. Study 1**

Study 1 involved running focus groups to ask PWLD if they agreed with, and understood, each of the adapted psychotic symptom statements. The participants were then asked to choose one of the two corresponding best-fit symbols that they consider most accurately represented the psychotic symptom statement. Overall, five focus groups were held, giving a total of thirty-eight participants across all five groups.

The participants agreed with all the psychotic symptom statements. When choosing between the two best-fit Widgit symbols, the participants showed a clearer preference for some of the symbols, especially when the statement had a more concrete meaning. Whilst other symbols received a more even distribution of responses. In addition to the presented Widgit symbols, some participants were able to offer suggestions on how the symbols could be amended to enhance the meaning of the psychotic symptom statement. The results from all the focus groups were used to develop a sort-card tool which comprised of fifty-four psychotic symptom statements supported by one Widgit symbol. The psychotic symptom statements were colour-coded into thought, feelings and behaviour cards.

### **7.4. Discussion of Study 2**

Study 2 used a qualitative research method, in the form of Interpretative Phenomenological Analysis (IPA), to build an understanding of the participants' lived experience of psychosis.

Nine people with learning disabilities (PWLD) were interviewed, using a semi-structured interview schedule that employed the sort-card tool developed in Study 1. The interview was divided into three stages. During stage one the participants were asked to recall their psychotic symptoms from memory alone. Data was collected regarding the individual's ability to independently report their own psychotic symptoms. In addition, the referring clinician was also asked to give a description of the participant's clinical diagnostic picture.

The second and third parts of the interview used the Easy Read sort-card tool to support the reporting of individual's experiences, with data analysed using IPA. Analysis in IPA should be from the bottom, meaning that the researcher generates codes *from* the data, rather than using a pre-existing theory to identify codes that might be applied *to* the data. IPA encourages an open-ended dialogue between the researcher and the participants and may, therefore, lead us to see things in a new light.

Five super-ordinate themes emerged from part two and three of the interviews.

1. Understanding of the sort-cards
2. Additional psychotic symptoms
3. Underlying causes
4. Additional symptom descriptions
5. The individual development of a timeline.

#### **7.4.1. Part one of the interview: symptom reporting**

The full onset of psychosis is typically preceded by a gradual prodromal period, such as anxiety, restlessness and hallucinations. However, the term prodromal derives from medical literature and implies a disease progression that cannot be disrupted. Therefore, the term 'early warning signs' is a more accurate conceptualisation and allows for the possibility of preventive efforts to intervene and arrest the development of a full-blown psychotic episode (Birchwood, Spencer, McGovern, 2000). This early warning sign approach seeks to identify

the earliest signs of impending psychotic relapse for an individual and to offer timely and effective intervention to stop progression towards active psychosis. Many people experience the onset of odd feelings, thoughts and perceptions a few months before any behavioural changes can be observed. However, it is difficult to recognise early warning psychotic symptoms, especially in PWLD and will, therefore, often go unnoticed by others until the person displays outward symptoms characteristic of a mental illness.

Determining exactly when an episode of psychosis begins can be hard, but these signs and symptoms are strongly indicative (NICE, 2014):

- Hearing, seeing, tasting or believing things that others don't
- Persistent unusual thoughts or beliefs
- Strong and inappropriate emotions or no emotions at all
- Withdrawing from family or friends
- A sudden decline in self-care
- Trouble thinking clearly or concentrating

The psychotic symptom-rich period is sometimes called the active-phase or florid psychosis. When psychosis occurs it often becomes a chronic condition that continues through the individual's lifespan with varying degrees of intensity.

For PWLD the recognition and identification of psychotic symptoms is often reliant on third-party reporting, as the person does not always possess the language skills to articulate their experiences. Furthermore, positive symptoms seen in the general population are not commonly reported in PWLD, probably because it is difficult to elicit disorders of thought or perceptions as there is no objective basis in reality (Royal College of Psychiatry, 2001).

So, for PWLD, there is a reliance on carers and relatives to give a corroborative history, together with direct observations of the person's behaviour and functioning in different settings to form the diagnosis (Myers, 2016; Hassiotis and Turk, 2012; Bradley *et al.*, 2011; Varghese and Banerjee, 2010; Raghavan

and Patel, 2005). However, when there is an overreliance on direct observations, and second-party reporting, the person's thoughts and feelings are not sought, and as a result could lead to diagnostic overshadowing and/or a lack of recognition of illness progression.

The first part of the interview, within Study 2, asked the participant to describe their psychotic experience, with particular relation to their thoughts, feelings and behaviours. Without any added prompts all the participants had difficulty articulating their experiences. In addition to the individual participant's own description, a clinical picture was sought from the referring clinician. The information obtained was notably scant with only a few psychotic symptoms being identified by either the participant themselves or from clinical reports.

In relation to feelings only three participants could identify related symptoms, which included anger, sadness and irritability. More noticeability both the participants themselves and the clinical picture described behavioural symptoms only. These mainly included self-harming behaviours or aggression towards others. When disturbances of thought were described they mainly pertained to auditory hallucinations. This symptom description is more likely to have been observed, as the person responds to persecutory thoughts, than being derived from the individual themselves.

From both the participant's conveyed symptoms and from the recorded clinical description, it was difficult to understand how a diagnosis of psychosis could have been reached for most of the participants. Moreover, three of the participants, Robert, Linda and Paula, had also received a diagnosis of emotionally unstable personality disorder, sometimes referred to as borderline personality disorder (BPD). In line with the ICD-10 diagnostic manual (World Health Organisation, 1992) individuals receiving a diagnosis of BPD should experience at least five symptoms from the diagnostic criteria, being:

- Feeling worried about being abandoned

- Intense interchangeable moods
- Not having a strong sense of who you are
- Difficulty making and keeping stable relationships
- Feeling empty
- Acting impulsively in ways that are damaging, such as using drugs or binge eating
- Regular self-harming, suicidal threats or behaviour
- Intense anger that is difficult to control
- Paranoid thoughts when stressed.

For many PWLD, these characteristics may not be the result of BPD but could just as easily be aligned to their deduced cognitive ability or poor social circumstances rather than a symptom of the disorder. Likewise, some of the diagnostic criteria for BPD, such as paranoia, anger and interchangeable moods, are just as likely to be the result of a psychotic illness, which if diagnosed affectively, can be treated with medication. In addition, an individual may have learnt poor coping strategies, such as self-harming or impulsive behaviours, to overcome the distressing experience of psychotic symptoms. Without a full description of the participant's lived experience the findings suggest a need to pigeonhole observed behaviours into a diagnostic criterion with little evidence to support the label. This finding is supported by the literature which identifies clinicians have diagnostic preferences and people are often given a range of diagnoses during their contact with mental health services (Van Os, *et al.*, 1999; Kirk and Kutchins, 1994).

For the participants that were able to give a more detailed description of their symptoms at this stage of the interview, they described feeling mistrusted by services on the accuracy of their reported lived experiences.

During the first part of the interview, Paula was able to narrate a detailed, unprompted, description of both her visual and auditory hallucinations, where she depicted seeing men with half a face, covered in blood. She also said, "*The*

*voice tells me I'm going to be like them, and it only goes away if I self-harm".* However, her diagnostic profile recorded pseudo-hallucinations due to levels of stress. Whereas, Robert recounted having his symptoms questioned as authentic and described, *"Although the doctors don't think I do, they think I imagine it, but I know when I hear voices"* (Appendix 24b, line 82).

#### **7.4.2. Super-ordinate theme: Understanding the sort-cards**

All, but two, of the participants were unable to read the sort-card symptom statements, so the statement was read out to the participants while the sort-card was placed on a table in front of them. The supporting Widgit symbol appeared to aid the individuals understanding of the sort-card symptom statement, acting as a reminder for the words that were not easily recognised. For example, Robert immediately recognised experiencing anxiety, with him relating to the beads of sweat depicted within the Widgit symbol to his own experiences.

For some of the participants there was a degree of uncertainty over the more abstract psychotic statements and therefore further clarification was required. However, once further interpretation of the statement had been offered the participants were able to relate the symptom to their own experiences. It should also be recognised that the sort-card tool, as with all Easy Read information, is not designed to be used in isolation and appropriate support should always be offered to ensure the information is understood and delivered in a way that meets individual needs.

The sort-card tool not only gave the participants the words to describe their experiences but appeared to facilitate a rapport between the participant and the interviewer, with the participants becoming more relaxed when the sort-card tool was introduced. There could be a number of reasons for this. It may have been because the participants were familiar with the format of the Easy Read information, supported with a Widgit symbol, and consequently felt at ease with the presented material. It may have been because the sort-cards acted like a



cognitive credit card, reducing the participants concerns in articulating their experience and which aided working and explicit memory, active recall and cognitive processing. Or, and hopefully the most foremost reason, the sort-card tool acted as a conduit for an equal interface between the participant and the interviewer, which in turn eliminated any power imbalance and reduced any underlying stress, so the participant felt comfortable to narrate their lived experience. What is certain, is that all the participants were able to relate to and identify significantly more symptoms from their lived experience when they used the sort-card exercise, compared with reporting their symptoms from memory alone.

#### **7.4.3. Super-ordinate theme: Additional symptoms**

As indicated in the literature (NICE, 2014) there are four main symptoms associated with a psychotic episode, being hallucinations, delusions, confused and disturbed thoughts, and lack of in-sight and self-awareness. However, as with all human experiences, no one person's difficulties, or ways of coping with them, are exactly the same as anyone else's. Individuals will have their own unique set of symptoms and experiences, according to their particular circumstances. This was especially evident when the participants were introduced to the sort-card tool, compared to recounting their lived experience without the tool, as they began to recognise and articulate a rich account of their psychotic illness. The participants narrated an in-depth description of their bespoke symptom presentation, including additional symptomology that was not included within the original sort-card set.

Most notable, was the lack of acquiescence bias that has traditionally been associated with PWLD. This perception that PWLD are inherently prone to acquiescence (answering yes to a question regardless of the content or to give the response that the participant thinks the interviewer wants to hear) was mainly supported by studies within the 1980's (Atkinson, 1988; Gowlands and Hulbert, 1983; Sigelman, *et al.*, 1980; 1981a; 1981b; 1982; 1986) and 1990's (Rapley and Antaki, 1996; Heal and Sigelman, 1995; Clare and Cudlonsson,

1993). From their research, Sigelman and colleagues reported that acquiescence in PWLD occurred in as much as fifty-six percent of their research samples and concluded that acquiescence bias and recency bias was negatively correlated with IQ and became more pronounced with more abstract and subjective questions.

However, acquiescence bias or recency bias was not evident within this research. The participants did not agree to experience a psychotic symptom, without protest. In fact, the opposite was observed, with participants actively correcting the statement contents to ensure that they had an accurate description that reflected their lived experiences. This self-reporting was more aligned to findings from Rapley and Antaki's (1996) study, who advocated that the traditional view of PWLD being submissive, willing-to-please and acquiescent is not sustainable. Moreover, other research suggests that PWLD require intermittent checking of their understanding as they are more unlikely to seek clarifications leading to an assumed false demeanour of their perception (Hurley, Tomasula, Pfadt, 1998; Bates, 1992). Once again, the findings from this study did not support this opinion, with the participants actively seeking clarification and asking for a psychotic statement to be explained further.

In identifying additional symptoms, the participants reported one of three things. They either described a different interpretation to the statement on the sort-card, or they reported a slight variation to the symptom statement, or they identified a completely new symptom that was not included within the sort-card tool. For example, for the symptom statement '*I do not eat as much*', Sally and Paul both stated that they actually ate more food when mentally unwell. Jim and Robert, on the other hand, reported that they experienced a loss of appetite to the extent that they stopped eating altogether. Robert said, "*I don't eat at all.....because I won't eat*" (Appendix 24b, lines 274 and 279). These symptom description variations were also seen in themes such as talking and smiling to themselves and social withdrawal. For the symptom statement, '*I talk and smile to myself*', both Tilly and Jim both reported that they would talk to

themselves but did not feel that they would smile. For the symptom statement, '*do not see people as much as used to*', Tilly reported withdrawing from others by not answering the door or the telephone.

#### **7.4.4. Super-ordinate theme: Underlying causes**

It was very poignant to hear the level of emotional upset and trauma that the participants described around the events that led up to them experiencing a psychotic episode, with the interviews providing an insight into the challenges they had faced. Several of the participants relayed experiences of deep emotional anguish as they described their psychotic experiences. The findings were striking in the extent to which the participants experienced emotional distress based on traumatic events in their lives.

Although it is generally accepted that learning disability, in itself, brings increased vulnerability to mental health problems (Grey, *et al.*, 2010; Cooper, *et al.*, 2007; Richards, *et al.*, 2000) the findings highlighted that the participants were able to describe additional stressful life event cursers, such as bereavement, abuse and bullying. Evidence suggests that psychosis can be the result of an accumulation of stressful life events, particularly abuse (Varese, *et al.*, 2012; Read and Bentall, 2012). This was palpable in the findings, which illuminated complex trauma (traumatic stressors that are interpersonal or caused by others) experienced by Paul, Robert and Keith. Robert described physical abuse from his parents and Keith portrayed being bullied and subject to physical violence from members of the local community. Rather than creating conditions of protection and security within a relationship, abuse by primary care givers became the cause of their distress and created insecurity and states of ongoing vigilance and anxiety (Herman, 1992). During the interview Paul also described the abuse he suffered from his paid care givers and Robert narrated how he was a victim of a robbery. The robbery had been such a significant event in his life that he disclosed resorting to carrying a knife as a form of protection.

It was sobering to consider the myriad of painful life events and the consequence of unmanaged emotions which resulted in a deterioration in the individual's mental health. The participant's level of emotional distress was considerable, to the extent that some had resorted to self-harming behaviours and suicide attempts, which had later been labelled as a personality disorder, which in turn had rested the fault back on the individual. This was reflected within the participants chosen symptoms, with eight participants reporting that they felt sad, six said that they felt helpless, seven identified feeling that they could not cope and six related their symptoms to a perception of being punished.

When individuals find it difficult to make sense of what is happening to them they can turn to unhealthy coping strategies, such as to drugs or alcohol use or withdrawal from family and friends. Research has confirmed that the way people make sense of and react to their experiences can be important in determining how distressed they become (Peters, *et al.*, 2012; Morrison, 2001). Several participants indicated they were dealing with overwhelming emotions for which they lacked appropriate coping skills. Robert talked about using alcohol and cigarettes as a form of coping strategy for his symptoms, although he added the caveat, "*But I drink two percent alcohol*" (Appendix 24b, line 106). He continued to describe needing alcohol to help him sleep, saying, "*I make sure I have quite a few and then get me head down, and it help me to sleep then. If I try to sleep without drink I can't sleep. Like today I were gonna have a drink, so I could sleep before I came here. And I didn't have a drink, and when I tried to have a sleep I couldn't*" (Appendix 24b, line 108). Robert's presentation also switched from hopeless and despair to him using aggressive descriptions to describe the traumatic robbery. When he started to recount his experience his tone changed, with him aggressively stating, "*Yea, and the coppers shouting me saying you with the big black coat. Police. I turned round and went fucking what. I said you want a fucking smack between the eyes? And he said just calm down. I were really fuming I were. Boom, between the eyes, I punched me, I punched me face*" (Appendix 24b, line 38). However, later in the interview his

tone switch to helplessness, saying, *“I often phone the team....but none of them come out and see me anymore. Even if I’m feeling I wanna kill myself”* (Appendix 24b, lines 66 and 68).

Paul had been particularly traumatised by an abusive care provider who had stolen his money and had refused to support him to attend his mother’s funeral. As a direct result, his mental health declined, and he began to display behaviours that challenged others. This change in behaviour presentation led to a breakdown with his family relationships and police involvement. Traditionally, recognition of grief and loss was neglected in PWLD as they were considered incapable of experiencing such emotions (Dodd and Guerin, 2009). Carers and staff still underestimate or ignore the impact of loss on the individual (Bennett, 2003; Oswin, 1991; Bicknell, 1983). Being excluded from events prior to death and not attending the funeral was historically common for PWLD, but it is now recognised that this can lead to atypical responses to bereavement (Summers and Witts, 2003).

Current research suggests that psychosis is often a natural reaction to traumatic events and abuse that individuals have been subjected to (Longden, *et al.*, 2012; Read and Bentall, 2012; Johnstone, 2011; Moskowitz, *et al.*, 2009). This reaction is often referred to as the ‘psychological process’, or the way we experience, interpret and react to the world and others. In particular, certain life events are associated with certain psychotic experiences, such as childhood sexual abuse being linked to hearing voices, whereas those brought up in institutional care are slightly more prone to experience paranoia (Bentall, *et al.*, 2012). The literature goes on to suggest that there are a variety of reasons people may hear voices, with some auditory experiences being related to memories, especially hearing a voice of someone who was abusive or critical in the past, with the voices sometimes taking on identities similar to real people in the person’s past (Hayward, 2014). For the participants that described distressing auditory hallucinations the Maastricht Interview (Corstens, *et al.*, 2009) could be a valuable tool to support them to obtain a deeper

understanding of their experiences. The Maastricht Interview was initially designed by the Voice Hearing Network as a questionnaire to elicit information from people who hear voices but has since proven a useful tool to explore the lived experience of the voice hearer.

Another notable finding was the lack of perceived professional support during the early stages of an individual's psychotic presentation. Joyce, Sally's mother, described her anguish at trying to obtain professional help as her daughter's mental health started to decline and felt her lack of isolation was a contributing factor to her poor recovery. As identified within the literature review, this lack of appropriate support was noted as being problematic in the survey undertaken by the National Alliance on Mental Illness (2011). In the survey results the authors concluded that approximately twenty percent of both individuals who experience psychosis and their families felt that no one helped when the onset of symptoms occurred. The authors continued by reporting that this issue received the single greatest proportion of responses to the surveys question about who had been the most helpful, suggesting a high level of isolation and desperation.

Another significant finding was that all the participants lives were bereft of friends and social support, with their only support being provided by either paid carers or direct family members (Robertson, *et al.*, 2001). They also described that they did not necessarily talk over their experiences with their limited support network. Tilly explicitly referred to this when she discussed her care plan by stating, "*I don't normally tell them*". (Appendix 29b, line 473).

#### **7.4.5. Super-ordinate theme: Additional symptom description**

Once aided with the sort-cards the participants were able to give a rich and detailed account of their experiences. They appeared to gain a thematic and semantic understanding of their symptomology to articulate their lived experiences. They were not only able to identify the symptoms that related to their personal experiences from the sort-card statements, but the participants

also offered unprompted thick descriptions of their individual stories. In undertaking this exercise twelve super-ordinate themes emerged. Three of these themes were related to feelings, being; feeling more religious, changes in feelings and emotions, and feeling as if they were far away, in a different world. Four of the themes related to thoughts. These included, thinking they might be someone else, being unable to stop thinking about something, having strange feelings in their body and thinking that a part of them had changed shape. Only two themes emerged around behavioural symptomology, with the participants identifying that they acted like they were being watched and having that they had difficulty sleeping.

From the findings, it became apparent that in using the sort-card tool, the participants were developing their own individual formulation. In comparison to diagnosis, formulation enables the development of a deeper understanding of the person's illness idiosyncrasies and, in turn, supports a more personalised intervention approach (Ingham, *et al.*, 2013; Macneil, *et al.*, 2012). A formulation is a way of exploring the personal meaning of the event, relationships and social circumstances, together with identifying underlying distress. Unlike a diagnosis, which is beginning to be regarded as a simile for labelling, oversimplifying and pigeonholing mental illness, formulation is based on the assumption that, however extreme, unusual or overwhelming the nature of distress, at some level it can all make sense (Butler, 1998). The sort-card tool provided the instrument to begin developing an individual formulation, which is concerned with working closely with the individual to develop a shared understanding of the context and impact of their difficulties, to make sense of their experiences (Cooke, 2000). Gaining a deeper understanding of the person's lived experiences is especially important when supporting PWLD who have complex needs; when traditional interventions have been unsuccessful, or when faced with a paucity of empirical evidence for responding to the unique kaleidoscope of individual needs (Macneil *et al.*, 2012).

The sort-card tool enhanced the participant's ability to narrate and build on their experiences and can be directly compared to the 'quilt' metaphor, which was identified from an account by a parent of a child with Down's syndrome when describing the highs and lows of parenting, in which they wrote:

*'I would say it has been more like crafting a quilt. The quilt is woven from experience over time. Each experience you have becomes a block in the quilt. When you have only one or two blocks in that quilt (a few experiences), the one or two blocks truly stand out and you can't quite imagine the end product. However, as more and more blocks are added, the quilt becomes bigger, the pieces start to come together, and it begins to take form'*

(Andrews and Istvanffy, 2012, p172)

#### **7.4.6. Super-ordinate theme: Timeline**

In part three of the interviews, the participants were asked if they could arrange their chosen symptoms into a timeline, with the first symptoms that they experienced being placed at the top of the timeline and the last symptoms at the bottom. This was to ascertain if they were able to develop a unique individualised relapse signature. This part of the interview proved the most challenging aspect of the exercise as the participants were relying on memory recall at a time when their perceptions were often impaired. In addition, learning disabled individuals have problems with receiving, processing, analysing and storing information. Due to these difficulties individuals may be unable to memorise sequential information, such the days of the week, be unable to generalise new concepts to other areas of learning and may be unable to put facts together to see the big picture.

Despite the initial difficulties in understanding the concept of the exercise, the participants quickly identified the process required for them to undertake the exercise, with them readily moving the sort-cards up and down the timeline, positioning them and repositioning them, until they had them all in the correct position. As the participants went through the individual sort-cards for the



second time, they were able to recall additional details of their symptomology which galvanised their previous descriptions and allowed for them to reflect on their journey of recovery, which in turn helped develop an awareness and acceptance of their symptoms.

Five of the participants felt they experienced some of the symptoms all of the time and were, therefore, unable to place these symptom statements in a sequence. Whereas, all the participants had difficulty placing their symptoms in a precise linear timeline. Instead, they tended to group the symptoms around the categories of beginning, middle and end.

The findings highlighted that, by using the sort-card tool, each participant was able to identify between thirty-two and forty-four psychotic symptoms pertinent to their own experiences. As seen in figure 18.

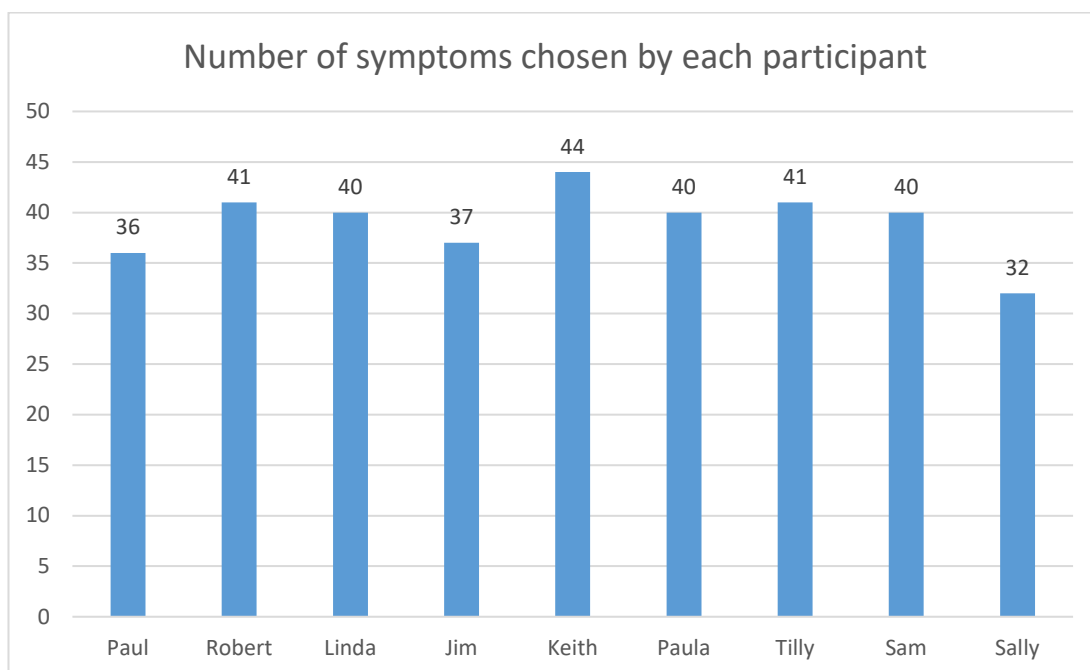


Figure 18: Total number of symptoms chosen by each participant.

In total, the participants identified experiencing a total of 107 behavioural symptoms, 104 thought symptoms and 123 feeling symptoms.

From listening to the participants' experiences, it became apparent that they began to develop a '*symptom intelligence*' or '*illness perception*'. The work on illness perception was developed by Howard Leventhal (Leventhal, *et al.*, 1997; Leventhal, Nerenz, Steele, 1984) when they presented Self-Regulation Theory, in which he proposed that when an individual understands their symptoms and illness they can understand the process that drives their coping mechanisms and emotional responses to the health threat. This theory was initially utilised within physical illness but has more recently been applied to mental health disorders (Broadbent *et al.*, 2008; Holliday *et al.*, 2005; Lobban, Barrowclough, Jones, 2004; Pollack and Aponte, 2001). In Pollack and Aponte's (2001) study they reported themes of 'coming to terms with the diagnosis' and 'the importance of personal metaphors. Pollack and Aponte (2001) also recognised that the illness presentation changes overtime and advocated that it is best to elicit psychotic symptoms during remission, so the individual can make better sense of the illness. They also concluded that allowing the patient to tell their story can be therapeutic as it allows the individual to consider new issues and clarify aspects of their illness.

## **7.5. Care plans**

All of the participants made a request for their identified psychotic symptoms to be incorporated into a personalised care plan (Appendices 22a to 30a). To offer an explanation of the content of the Care Plan an over-arching statement was written as an introduction, as illustrated in figure 22.





<b>About my psychosis?</b>	
	Psychosis is a type of mental illness where someone doesn't seem to be themselves
	There is often 3 to 4 weeks between the start of early signs to full psychosis
	People usually have the same thoughts, feelings and behaviours each time they become ill.
	This plan describes my thoughts, feelings and what I do in each stage, from the beginning to the end, so I can get help quickly.
It describes my thoughts (green), my feelings (pink) and the things I do (blue).	

Figure 22: Care Plan over-arching statement.

Paul requested that his Care Plan could be produced in the style of PEC cards (Appendix 22a). Tilly requested two copies of her Care Plan, one with large Widgit symbols and text and another version with smaller Widgit symbols and text that could fit on to two A4 pages (Appendix 29a). Sam asked for a smaller, two-page version only, and asked for an additional laminated copy of his Care Plan, so he could take it into hospital with him (Appendix 30).

This request seemed to stem from the participants desire to effectively self-manage their psychosis and to have their symptoms validated within their own relapse signature. These findings affiliate with the NHS Five Year Forward View for Mental Health (2006), the concept of 'patient activation' and the theory of 'illness identity'. The NHS Five Year Forward View has an emphasis on helping people manage their own health, which gives individuals the knowledge, skills and confidence to recognise and develop their own strengths and abilities in self-management of health issues. Whereas, the notion of patient activation is closely linked to the principles of person-centred care and enables the delivery of personalised care for people with long-term conditions (Hibbard and Gilbert, 2014; Greene and Overton, 2013; Mulley, Trimble and Elwyn, 2012). Also

parallel to these principles is the concept of '*illness identity*', which advocates when an individual is supported to identify with their mental illness they can, in turn, improve hope and self-esteem (Yanos, *et al.*, 2010).

## 7.6. Additional areas for discussion

During the interviews, some additional issues, that were not included in the interview schedule, were observed and are worthy of note. A marked finding was the participants' understanding of the more abstract concepts within the sort-card symptom statements. People with learning disabilities are reportedly highly concrete thinkers and often have difficulty understanding abstract concepts, such as the concept of time (Owen and Wilson, 2006). However, the participants were able to understand and relate to abstract concepts, with eight participants identifying with the statement '*I act like someone else*' and six out of the eight felt that they experienced the symptom towards the end of their illness, when their psychosis was florid. Four of the participants identified with '*I feel far away, in a different world*', with three placing this symptom within the active stage of their psychosis.

Although considerable time and effort had been taken to develop the sort-cards into an Easy Read version, supported by a Widgit symbol chosen by PWLD within the focus groups, one sort-card statement and Widgit symbol was found to be consistently confusing for many of the participants. The statement, '*my senses seem better*', illustrated in figure 23, was difficult for the participants to understand and required additional explanation.

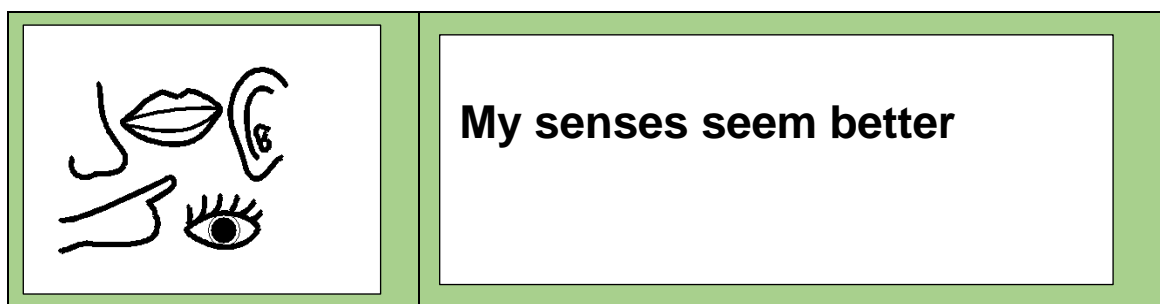


Figure 23: Sort-card that participants found difficult to understand.

In retrospect, this statement should have been broken down into five separate sort-cards, with an individual sense on each, for example, '*my hearing seems better*'.

During the interviews, a number of participants were prompted by the sort-card statement to articulate further personal descriptions of their psychotic experience. These additional descriptors were added to the participant's Care Plan, under the corresponding psychotic symptom statement. As illustrated in figure 24.


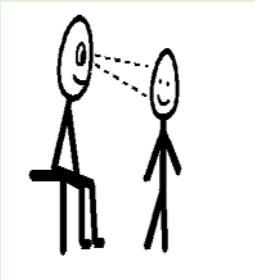
	<p><b>I hear voices</b></p> <p>The female voice (Kate) tells me I will be like the men. It goes away if I cut myself</p>
	<p><b>I see things other people cannot see</b></p> <p>I may make a bed for a little boy that is not there. I can see a man who smokes. I say there are eyes in the wall. I think someone is outside or in the cupboards</p>

Figure 24: Example of additional descriptors added to a participant's psychotic symptom statement.

After his interview, Keith wrote to the researcher expressing his thanks for being helped with his mental health problems.

The Care Plans were written within a week of the interview and posted to the participant, along with a covering letter thanking them for participating in the

research, and a thankyou card, which expressed the researcher's appreciation of their time.

## **7.7. Implications for clinical practice**

People with learning disabilities are at least as susceptible to mental health problems as the rest of society and are probably more vulnerable due to the increased risks associated with social, psychological, economic, emotional and biomedical factors (Burke, 2014). Many PWLD live in poverty, have few friends and have additional long-term health problems, all of which are associated with mental health problems (Hardy and Woodward, 2010; Martorell and Tsakanikos, 2008). In addition, many PWLD tend to have poorer coping mechanisms making them vulnerable to the impact of life events such as bereavement.

The first step in identifying a mental health difficulty is to have one's problem recognised and in this respect people with learning disabilities are at a major disadvantage compared to the general population. There is a general assumption that most people with learning disabilities are unable to recognise that a problem exists, or to articulate their distress if they do recognise it (Moss, 2001). There is also an assumption, that due to poor verbal ability many people with learning disabilities are unable to be interviewed, so there has traditionally been an over reliance on carers and relatives to give a corroborative history, together with direct observations of the person's behaviour and functioning in different settings to form the diagnosis (Myers, 2016; Hassiotis and Turk, 2012; Bradley *et al.*, 2011; Varghese and Banerjee, 2010; Raghavan and Patel, 2005).

Amongst the most widely used tools to help assess for mental health issues in PWLD is the PAS-ADD Checklist (Revised): a mental health questionnaire, designed to be used by care staff and families of PWLD (Moss, 2002). However, the Guideline Committee members for the NICE guidelines on mental health problems in PWLD (NICE, 2016) found that the neurotic, depression and

schizophrenia symptoms subscales had little supporting evidence and considered the PAS-ADD Checklist to be essentially a screening instrument and not suitable for assessment purposes.

The findings of this research have direct implications for clinical practice, especially in relation to assessing psychosis in people with mild learning disability. In using an Easy Read sort-card tool PWLD are not only able to communicate their experiences and identify their individual symptomology of psychosis but they can also give a rich description of their lived experiences.

Through their narratives, the participants in this research demonstrated that they can not only identify their symptoms, but they are able to recognise when the symptoms manifest. By understanding the lived experiences and the stories behind the experiences, services can begin to make sense of them creating shared understanding and appropriate interventions.

The findings of this research also highlight the importance of understanding traumatic events that lower mental resilience. The use of formulation, rather than being tied to a strict diagnostic criterion, would lend itself to understanding the individual's unique experiences. In developing individually tailored, and regularly reviewed care plans, the person would be able to be actively involved in their relapse signature. Included within the relapse signature services should support the individual to develop a relapse prevention plan or stay well plan. These plans should contain a 'relapse drill' or an action plan containing how timely support can be offered by services that correspond to the type of warning sign.

## **7.8. Conclusion**

The scarcity of research on the self-reporting of psychotic symptoms experienced by PWLD limits comparisons between the depths of the participants' expressed lived experience with other studies. However, psychosis does not suddenly appear. As with other life conditions, such as asthma and

diabetes, there is often a 'run-in time' and early intervention is always more effective. The findings of this research clearly suggest that individuals with mild learning disabilities can articulate their lived experiences of psychosis. Furthermore, the most poignant finding from the research was the significant levels of trauma that had been experienced by the participants and the direct impact this had on the participant's resilience.



# **Chapter 8: Conclusion**

## **8.1. Introduction**

This research set out to explore if PWLD could report their own psychotic symptoms. This chapter will recapture the issues raised in this research and draw together the points and concepts discussed to allow recommendations to be presented. The research's strengths and limitations, together with personal learning, and suggested areas for further research, will also be discussed.

## **8.2. Focus of this research**

The research consisted of two interlinking studies, supported by preliminary planning. The focus of the first part of the study was to develop a sort-card tool to be used with PWLD, who have experienced a mental illness, to help them to report their experience of psychotic symptoms.

In Study 1, focus groups were utilised to develop an Easy Read psychotic statement sort-card tool. The results showed the participants could offer a valuable contribution in the development of Easy Read information to be used across the learning-disabled population. In particular, the focus group participants were able to offer suggestions on how the existing symbol sets could be adapted to further enhance the understanding of abstract concepts, demonstrating that focus groups can be a beneficial resource in eliciting the views of PWLD.

In stage two of this study, nine participants with mild learning disabilities and a diagnosis of psychosis, were interviewed using the sort-card tool developed in Study 1. The interviews were undertaken in three parts with data from part two being analysed using Interpretative Phenomenological Analysis (IPA). As IPA

utilises *phenomenology*, *hermeneutics* and *idiography* it allowed for the exploration of the perspectives and experiences of the individual participants by focusing on personal meaning and sense-making, rather than generating theory.

The findings showed that all the participants were able to undertake all three stages of the interview process. In part one of the interview it was evident that the participants had difficulty identifying and articulating their full range of psychotic experiences due to their limited verbal repertoires. With the introduction of the Easy Read sort-card tool, the participants were able to label and frame their individual experiences and, in doing so, empowered them to narrate a detailed description of their psychotic symptomology.

### **8.3. Strengths and limitations**

This research may be deemed successful in relation to its exploratory aims and effective use of IPA, showing its appropriateness as an approach for PWLD, which will influence clinical practice and will add to the body of qualitative knowledge. The IPA approach was selected for its reflection of the researchers ontological, epistemological and methodological beliefs and because it is heavily reliant on co-construction and a double-hermeneutic inquiry. This phenomenological, *hermeneutical* and *idiographical* approach has been shown to offer a powerful method to access the experiences of PWLD, to enable them to articulate their experiences in their own words and to recognise them as experts on their own lives.

A strength of the methodology was in the use of an approach that allowed in-depth exploration of participant's experiences. Each interview was analysed vigilantly to ensure the participant's experiences were captured and to facilitate a useful level of interpretative engagement with the text. The small sample size allowed time for this depth of analysis and ensured the voices of all participants

were heard, thus meeting the idiographic commitment of IPA (Smith, *et al.*, 2009).

It could be argued that in using the Easy-Read card tool could have introduced an interview schedule that was too rigid which could have had some effect on the themes interpreted. However, the super-ordinate and sub-ordinate themes identified suggest otherwise. In fact, the Easy Read resource enabled PWLD to articulate their lived experiences with additional themes such as additional symptoms and descriptions being elicited.

Although based on the experiences of people with a mild learning disability, a further potential application of the study is that the findings may apply to other marginalised and stigmatised groups such as those with long-term mental health problems or autism without a learning disability. Further research is needed to confirm this view.

Nevertheless, limitations were noted in the course of the research. These included challenges related to the nature of recruiting participants, data collection and the amount of data obtained.

Within Study 2 the findings are based on the experience of nine participants, and the researcher's own interpretations of the data. It is acknowledged that the researcher took an active role in the research process and interpreting the findings. It is recognised that personal preconceptions have not been completely bracketed, however a reflective and reflexive approach has been adopted. It is accepted that this provides only one perspective from a number of possible interpretations, given the amount of rich and varied data obtained. The findings do not define an absolute presentation, but rather, seek to frame data in the context of the research aim.

Transparency has been aimed for by outlining the procedures and presenting transcripts to allow the reader to reflect on the interpretations and consider possible alternatives.

Although the sample size for Study 2 was larger than some of the other IPA research studies, caution should be used when attempting to generalise findings to the whole of the learning-disabled population. This is not to say IPA is opposed to more general claims for larger populations; it is just that it is committed to the painstaking analysis of cases rather than jumping to generalisations (Smith, 2011). The aim of this study was not to make generalisations but to open up this area to scrutiny and raise new questions.

There is a recognition that a number of eligible service users for Study 2 declined to take part, with one participant withdrawing from the study during the interview process. It is difficult to comment on the effect this may have had on the research findings.

Another limitation is that the research sample recruited participants from a learning disability specialist health service, yet the majority of PWLD do not access specialist services and there is no way of knowing whether a non-service sample would have yielded a different set of findings.

There is also an issue with using a third party to make initial contacts with potential participants as they may have complied because of wanting to please the third party. To counteract this difficulty, the participants were reassured that it was their choice to participate. With this in mind, it is also acknowledged that the sample could be seen as self-selecting, with the findings only reflecting the experiences of individuals willing to be involved in the interviews. Once again, to maximise transparency, the narratives have been provided in the appendices to allow the reader to construct their own interpretations.

## **8.4. Implications for future research**

Overall the findings offer several opportunities for future exploration. This research included data analysed using IPA, which used a small sample size. The research was also undertaken within the confines of the resources available in relation to a professional doctorate (such as time and funding) and replication with larger numbers would be desirable.

More qualitative research into the self-reporting of the views of service users on life events, coping skills and their perceptions of their own mental health is needed.

Psychiatry has traditionally emphasised the importance of diagnostic categories, to guide treatment options and predication of outcomes. In reality, diagnosis is often based on selecting from a diagnostic list in which some items are present, and others absent. This can result in two people, with the same diagnosis, having few and in some cases, no symptoms in common. This research has shown that diagnosis alone tells us little about causation of a psychiatric disorder; which intervention should be adopted; and offers no information about the person's experience of their disorder and how they can be more empowered to manage their well-being. This research has underscored the need to understand the diversity of etiological factors, such as trauma and social stressors, to provide quality care. One of the most significant questions that arose from the findings is that there is a need to move away from this traditional way of providing services.

One approach to achieve a more person-centred way of working is to adopt the use of formulations across all disciplines. Formulation is a way of summarising meanings and of negotiating shared ways of understanding; a process of ongoing collaborative sense-making. Formulation can assess predisposing, precipitating, perpetuating and protective factors for the individual. Formulation

could, at least in principle, be seen as a way of reintroducing personal meaning that take into consideration the person's personal and social contexts. More research is needed in the use of formulation and mental health for PWLD.

Future research could also be conducted into adapting an Easy Read version of the Maastricht Interview to support PWLD pinpoint precursors to their mental health decline, and to connect the possibility of previous traumatic events to voice hearing experiences.

## **8.5. Evaluation of the research and recommendations**

In evaluating the research, the quality criteria, defined by Smith (2011) has been considered. The research focused on a specific group of PWLD, those with mild learning disability and one particular experience, that of a psychotic episode. There was a specific and *clear focus* on the aim of the study with all the participants understanding the purpose of the study. *Strong data* was derived from high quality interviews, supported by an Easy Read sort-card tool, which allowed for the narrative of individual lived experiences to be captured. The analysis offered *rigour*, with five super-ordinate themes being identified. The super-ordinate themes and corresponding themes were discussed at length, offering *elaboration of each theme*, with transcripts being provided for transparency. The presentation of the themes content was *interpretative and not just descriptive*, with analysis of the data seeking to reveal each participant's lived experience. This analysis included *convergence and divergence*, with the immersion into each individual's transcript before consideration of the whole corpus was undertaken. Although common themes were identified, the individual was not lost within this and individual characteristics were highlighted throughout the study. The analysis was *carefully written* to stay close to the participant's views and meaning-making of their experiences, with the aim of engaging with the reader so they could see the world through the eyes of the participant, emerging with an empathic and deeper understanding of their lived experience.

Ontologically, this research informs us that individuals with mild learning disabilities can articulate their lived experiences of psychosis. The results demonstrate that PWLD are able to narrate a rich description of their experiences and can go on to develop a symptom timeline that can inform their relapse signature. Another important aspect of this study highlighted that some participants had experienced significant levels of trauma which had a direct impact on their mental health resilience.

It is also worthy of note, that despite the traditional view that PWLD are inherently prone to acquiescence this was not evident within this study. In fact, the opposite was observed, with participants actively seeking clarification and offering a different perspective to ensure their voice was heard.

The findings of the research have considerable importance for clinical practice and highlight several recommendations.

1. The use of formulation, as favoured by Clinical Psychologists, would lend itself to other professional groups, to enable an understanding generated from the individual unique experiences. It is recommended that, to challenge services that are wedded to a strict diagnostic criterion, training and supervision should be developed for clinical teams to increase awareness and understanding of emotional and psychological well-being of PWLD. This training should incorporate the social model of disability; how trauma has a relationship to mental health resilience; and how formulation can support us to understand this lived experience.
2. This research has shown that PWLD are capable of engaging in a process to aid them articulate their mental health symptoms and lived experiences. Another recommendation is to develop a Stay Well plan (or Care Plan), along with the individual, that incorporates their relapse signature. This should also include the individual's relapse drill and how this stepped intervention would provide timely and appropriate support for the person.

3. Given the prevalence of poor mental health in PWLD preventative interventions would be advantageous. It is therefore recommended that a Staying Mentally Well course should be developed for PWLD to educate them in strategies that are known to help maintain good mental and emotional wellness, such as sleep hygiene, exercise and healthy eating.
4. This research has shown that PWLD can not only help to develop Easy Read information but that their input is invaluable to enable that information to reach the widest audiences. It is, therefore, recommended that links with advocacy groups should be firmly established with clinical services to enable them to act as a reference group that has input into policy and practice material.
5. As the focus groups showed competence in designing their own symbols to support abstract concepts of psychosis, their suggestions should be shared across a wider audience. It is recommended to liaise with Widgit Software so the suggested new symbols and changes to the existing symbols could be incorporated into the Widgit symbol set.

## **8.6. Reflection on undertaking the research**

The motivation for this research evolved from working within the field of learning disability nursing for over three decades. There are many places to begin a story. This research began with the authors clinical work of supporting PWLD to access generic services, in particular mainstream psychiatric services. Although it is recognised that assessing mental health difficulties in this population can be complex, especially as the diagnostic criteria is not adapted for the developmental and verbal level for PWLD.

As already discussed in Chapter 2, psychiatric diagnosis, within the general population, depends primarily on the account given by the subject, which relies on a description of complicated internal and subjective feelings and cognitions. It became increasingly noticeable that PWLD were not always offered an



equitable service, with their presentation often being attributed to their learning disabilities. The difficulties of assessing health disorders in PWLD was confounded as standard assessment tools were not necessarily appropriate for this population. The question that was pertinent to the author was that if an appropriate assessment tool was available, and PWLD were empowered to do so, could they report their own psychotic symptoms? This self-reporting could aid diagnosis, confirm existing diagnoses and help to identify a relapse signature.

Within clinical practice there is still dominance towards positivist research, with an emphasis that data from quantitative research is gold standard. It is the author's view that truth and meaning do not exist in some external world but are created by the individual's interactions with the world. Surely, psychotic symptoms should be examined from the person's experiences rather than a decontextualised approach of symptoms of a disorder from a pathological and biological process, derived from social constructs.

The research intended to explore the lived experience of people with mild learning disability who have suffered from a psychotic episode within the context of their own articulated symptoms and, therefore, a qualitative approach seemed fitting. Within the remit of qualitative research, interpretation and meaning from individual lived experiences is key. Moreover, there was a desire to support PWLD to articulate the subtle and unique differences of their illness to help them access the appropriate support, at the appropriate time, and embrace a recovery approach.

The epistemological assumptions and methodological procedures of IPA were complementary to the researcher's position and was felt could be able to achieve this goal. Especially as it is aimed at capturing, as closely as possible, the way in which a phenomenon is experienced within the context in which the experience takes place (Giorgi and Giorgi, 2008b) by generating themes *from* the data, rather than using a pre-existing theory to identify codes that might be

applied to the data. It also encourages co-production between the researcher and the participants and can, therefore, lead us to see things in a new light.

Research is not just about identifying the epistemological assumptions; the methodology needs to be actually implemented. Before the research could be undertaken ethical approval was required. When applying for ethics approval it became evident that the process would be difficult and lengthy, especially as there was a higher level of scrutiny when involving vulnerable groups. This was not anticipated at the time of applying to the NHS Ethics Committee and resulted in numerous re-submissions before approval was granted.

Four years engagement with a single project leaves a lot to reflect upon. How has it affected me as a person? How has it affected those who agreed to take part in the research? How has it benefited PWLD? What is apparent, is the complexity of the research design, and for a novice researcher, this was challenging and time consuming. As challenging as it may have been in undertaking the research, there was awareness that a positive outcome for PWLD, who experience mental ill health, could be achieved. This enabled the research to stay on course.

The most rewarding stage of the research was meeting PWLD, who generously gave their time and experiences. In looking back at the data derived from the focus groups and in reading the transcripts, it has shown that PWLD have a wealth of information that can influence service provision and clinical practice. There were also obvious benefits for the participants themselves. The process of describing their lived experiences seemed to help them make sense of their experiences. Through telling their stories, the participants were able to communicate their experiences of psychosis, and in doing so, enabled others to understand the stories behind their experiences, leading to a reciprocal and supportive relationship between service receiver and service provider.

It was always important that the findings of the research could be used to influence not only personal practice but the practice of colleagues. The initial

aim was to establish if PWLD could report their own psychotic symptoms. This was achieved. What was also found, was a far richer quilt of data, which galvanised the relationship between traumatic life events and the effect these have on an individual's mental health resilience. This in turn, has a direct impact for personal clinical practice. Although the author still holds lightly to the theory of using diagnostic criteria to make a diagnosis, they are now much more open to considering the adoption of a formulation approach. The findings have already been presented to a regional Learning Disability nurse forum and are due to be presented at other professional meetings to influence a more person-centre clinical practice.

## 8.7. Dissemination

From research evidence we know that research is most effectively disseminated using multiple vehicles, ideally including face to face interaction. To ensure that the outputs from the research informs practice and thereby maximise the benefit to patients and the NHS, the following dissemination strategy has been developed for translating knowledge into practice.

- **Interactive workshops** with colleagues across the local mental health trust
- **Presentations** to colleagues across the East Midlands
- **Publications** on AAC tools to examine lived experiences; psychosis, trauma and presenting symptoms; user engagement and co-production. The following journals will be approached for publication:
  - Journal of Applied Research in Intellectual Disabilities
  - Advances in Mental Health and Intellectual Disabilities

This proactive dissemination strategy offers the breadth to reach out to multiple audiences and the depth to conduct more in-depth interactive work with key audiences such as NHS commissioners and provider staff to influence attitudes and behaviour change.

## **8.8. Conclusion**

This research was successful in providing key insights into the topic under investigation and has generated recommendations and ideas for future research. It was humbling to hear the many difficulties with which each participant struggled and there is admiration for their resilience and courage in the light of the adversities that they faced. It was a privilege to hear about their journey and to be witness to their empowerment, increased confidence and growing sense of self. Their stories have contributed to the growing literature needed to support PWLD to receive person-centred mental health care and has highlighted important considerations for clinical practice and service implications.

This research has represented the first qualitative exploration of people with mild learning disabilities experience of psychotic experiences. The emergent themes demonstrate a journey that each participant has travelled. Through their narratives, participants told their story of their experience in the context of their psychotic symptoms. The findings are likely to have a major contribution in reducing misdiagnosis and preventable hospital admissions.

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